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PERSON-CENTERED SHIFT HANDOVERS IN ONCOLOGICAL INPATIENT CARE

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Person-centered handovers in oncological inpatient care

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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ABSTRACT

Surveys show that patients are not sufficiently involved in decisions and planning regarding their own care, and patients have reported unfulfilled information needs in inpatient settings. To develop inpatient cancer care towards more person-centeredness, practices and ethics need to change. The nurse shift handovers have traditionally been performed secluded from patients, and without given structure. These handovers have been identified as opportunities for patient involvement, and different models of bedside handovers have been implemented and evaluated with varying results. Person-centered handovers (PCH) were developed in an attempt of combining the ethics and core components of person-centered care, and the practical task of performing the shift handover at bedside. PCH were implemented stepwise at three oncological inpatient wards at the Department of Oncology, Karolinska University Hospital. PCH include the patient, the on-coming nurse, the off-going nurse, and sometimes patients' visitors and nurse assistants. The main intentions with PCH were to promote structured, safe, and efficient handovers, provide an opportunity for patients and nurses to create a joint plan for the care, and to promote information exchange between nurses and patients.

The general aim of this thesis was to identify and describe consequences of introducing PCH in oncological inpatient care. Specific aims included to investigate whether PCH could influence patient satisfaction, patients' perceptions of information provision, health related quality of life (HRQoL), and to describe nurses' perceptions of working with PCH.

The thesis is comprised of three studies, presented in four different scientific papers. The first study (**Paper I** and **IV**) was cross-sectional with two points of measurement. Two of the inpatient wards served as a comparison group and practiced standard handovers during the study period, while PCH was implemented at the third ward after the first point of measurement. Adult patients cared for at the wards assessed their satisfaction with care by responding to the EORTC IN-PATSAT32 questionnaire, HRQoL with EORTC QLQ-C30, and perceptions of information with the EORTC QLQ-INFO25 module. Differences between the Comparison wards and the Intervention ward were analyzed with linear regression. Two years after the first study, a second data collection was carried out at the previous Comparison wards where PCH had been implemented about two years earlier, **Paper III**. Patients assessed their satisfaction with care and their perceptions of individualized care. Comparisons on patient satisfaction were made with data from the first study, and were performed with linear regression analysis. In **Paper II**, registered nurses working at the inpatient wards were interviewed about their perceptions of PCH. The data were analyzed with inductive qualitative content analysis.

In **Paper I** and **IV**, 325 patients (57 %) participated. Regarding patient satisfaction, no statistically significant differences were observed between the ward that employed PCH and those that used standard handover, apart from one exception. Patients' satisfaction on "Information exchange between caregivers" was statistically significantly at the intervention

ward than at the comparison wards. PCH were not related to patients' HRQoL or perceptions of information. In **Paper III**, 90 patients (75 %) participated. Patients who were cared for at wards where PCH were employed were more satisfied with nurses' information provision, and exchange of information between caregivers, than those who evaluated the wards when they used standard handovers. The interviews in **Paper II** revealed that nurses perceived patients to be both safer and better informed with PCH, but that they struggled in promoting patients' participation.

In summary, PCH had beneficial consequences on patients' satisfaction with information exchange between caregivers, and nurses' information provision, as compared to standard handovers. PCH were not related to patients' HRQoL or perceptions of information. The results indicate that sufficient time should pass between the first implementation phases and evaluations. The nurse interviews indicated that the actual delivery of PCH differed from the intentions, and that future implementations of PCH should focus on the ethical aspects of person-centered care.

LIST OF SCIENTIFIC PAPERS

- I. Kullberg, A., Sharp, L., Johansson, H., Brandberg, Y. & Bergenmar, M. **Patient satisfaction after implementation of person-centred handover in oncological inpatient care – A cross-sectional study.** PLoS One 2017, 12(4): e0175397
- II. Kullberg, A., Sharp, L., Dahl, O., Brandberg, Y. & Bergenmar, M. **Nurse perceptions of person-centered handovers in the oncological inpatient setting – A qualitative study.** International Journal of Nursing Studies 2018, 86: 44-51
- III. Kullberg, A., Sharp, L., Johansson, H., Brandberg, Y. & Bergenmar, M. **Improved patient satisfaction 2 years after introducing person-centered handover in oncological inpatient care.** Under revision in *Journal of Clinical Nursing* (2019).
- IV. Kullberg, A., Sharp, L., Johansson, H., Brandberg, Y. & Bergenmar, M. **Perceptions of information and health related quality of life among oncological inpatients in relation to person-centered shift handovers.** Manuscript submitted to *Patient Preference and Adherence* (2019).

CONTENTS

1	Introduction and foreword.....	1
2	Background.....	3
2.1	Oncological inpatient care	3
2.2	Shift-to-shift handovers	5
2.2.1	Bedside handovers	6
2.3	Person-centered care.....	12
2.3.1	What it is.....	12
2.3.2	Person or patient in the handover context	14
2.3.3	The ethics of person-centeredness.....	15
2.3.4	Participation and partnership.....	16
2.4	Person-centered handovers	17
2.4.2	Standard handovers.....	20
2.4.3	Implementing person-centered handovers.....	20
3	Aim.....	23
3.1	Rationale.....	23
3.2	Aims	24
4	Methods	26
4.1	Designs	26
4.2	Context	27
4.3	Participants and data collection.....	28
4.3.1	Paper I, III and IV	28
4.3.2	Paper II	29
4.4	Outcomes and instruments.....	30
4.4.1	Patient satisfaction (Paper I and III)	30
4.4.2	Perceived information (Paper IV)	31
4.4.3	Health related quality of life (Paper IV).....	32
4.4.4	Individualized care (Paper III)	32
4.4.5	Study specific questionnaire (thesis summary chapter).....	33
4.5	Data analyses	34
4.5.1	Paper I, III and IV	34
4.5.2	Missing data.....	36
4.5.3	Analysis of the study-specific questionnaire (thesis summary chapter).....	37
4.5.4	Data analyses in the qualitative study (Paper II)	37
5	Ethical considerations	39
6	Results.....	41
6.1	Participants	41
6.2	Patient satisfaction	42
6.2.1	Paper I.....	43
6.2.2	Paper III	43

6.3	Quantity of information, information exchange and health related quality of life	43
6.4	Aspects of patient safety	48
6.5	Individualized care	48
6.6	Nurses' perceptions of person-centered handovers	49
7	Discussion.....	52
7.1	Discussion of findings	52
7.1.1	Patient satisfaction	52
7.1.2	Information provision and health related quality of life	54
7.1.3	Individualized care.....	55
7.1.4	Nurses' perspectives	56
7.2	Methodological considerations	58
7.2.1	Quantitative data.....	58
7.2.2	Qualitative data.....	62
8	Clinical implications and general conclusions.....	66
9	Populärvetenskaplig sammanfattning.....	68
9.1	Bakgrund.....	68
9.2	Metoder	69
9.3	Resultat.....	69
9.4	Slutsats	70
10	Acknowledgements.....	71
11	References.....	75

LIST OF ABBREVIATIONS

EORTC	European Organisation for Research and Treatment of Cancer
HRQoL	Health related quality of life
ICS	Individualized Care Scale
OECD	Organisation for Economic Co-operation and Development
PCH	Person-centered handovers
PCC	Person-centered care
PCR	Personcentrerad rapport
SBAR	Situation Background Assessment Recommendation
SOP	Standard Operating Protocol
US	United States

1 INTRODUCTION AND FOREWORD

This doctoral thesis is focused on one specific nursing intervention, person-centered handovers (PCH). The idea of implementing and evaluating PCH at the Department of Oncology at Karolinska University Hospital first arose in 2012. Ward nurses complained about their shift handovers being too lengthy and inefficient, and at the same time, nurse managers saw an increasing number of patient safety incident reports related to communication. With this in mind, we performed a cross-sectional study among patients at the wards with the aim to examine the relationship between information exchange, patient satisfaction, safety and participation. We discovered deficits regarding central aspects of patient-nurse communication that might impact both safety and satisfaction outcomes (1). For example, just about half of the patients were aware of changes in medication, and a minority reported having been informed of, or that their risk of falling had been discussed, even though the nurses had assessed their fall risk as high. Perhaps most alarmingly, half of the patients stated that they were not able to influence the planning of their own care.

Inspired by the current focus on bedside handovers in inpatient nursing care, we developed a model based on a previously published Australian standard operating protocol (SOP) (2). There were concerns regarding the use of a checklist and a one-sided focus on patient safety issues as well as information primarily of interest to the nurses, rather than the patient's own preferences. When reading up on the philosophy and ethics surrounding the, by then fairly novel, research field on person-centered care, an appealing approach that could inspire our intervention was found. In an attempt to combine the need for a safe and efficient nurse handover, with the urge to promote patient participation and co-creation of care, we therefore developed person-centered handovers, the PCH project. The project itself represents a collaboration between ward nurses, nurse managers, and the research group. Our objective has been to implement and evaluate PCH as scientifically sound as possible, while managing the clinical realities of highly specialized inpatient care and the constant changes in the large university hospital organization.

This thesis is compiled of four papers evaluating PCH in different modes, based on three studies. The main outcomes were patient satisfaction and information provision as perceived by patients. Health related quality of life (HRQoL) was also investigated. A qualitative study is included, where 11 nurses from the wards were interviewed to provide information on PCH from the nurse perspective. In the background section of the thesis, I have included a brief literature review on various bedside handover models and their consequences for different aspects of care. When reading, it is important to remember the diversity in how these models were carried out with regards to context, intentions, checklists, and patient- or person-centeredness. Descriptions and reasonings on central concepts relevant for our specific

handover model are also included, hopefully contributing to shed light on and increase the understanding of PCH.

My first encounter with inpatient oncology care came about during my first employment as a registered nurse at Visby hospital in the spring of 2010. Spending time with and caring for the patients and their loved ones, in what for most of them were their darkest hours, turned out to be an amazing experience. During my time at the ward, I kept getting surprised each time a patient asked me why they were there, and what was going on, or what the plan was. ‘How can they not know this?’ I asked myself. We, the nursing and medical staff, constantly discussed the patients’ care plans, objectives for the admission, current status etc. How was it possible that we knew everything, or at least thought we did, while the person it concerned often seemed unknowledgeable? In retrospect, this seems like a naïve thought. Obviously, speaking about a person in a secluded room will not benefit that person’s knowledge, understanding or sense of participation. Rather, one should wonder what we missed out on by not including that person? Could we re-organize the way we provide health care in the inpatient context? Deciding the objectives, exchanging information, and distributing the responsibilities could all be performed in close collaboration and partnership with the patient and his or her loved ones. PCH do not provide a solution to all problems regarding these issues. At best, it could provide an opportunity for information exchange based on the patient’s own preferences. It is my firm belief, based on my research and my experience in oncology, that we need to reconsider how inpatient care is delivered.

Visby, 2018-11-01

2 BACKGROUND

2.1 ONCOLOGICAL INPATIENT CARE

In Sweden, approximately 500 000 persons live with cancer, and 60 000 were diagnosed in 2017 (3). About 70 000 individuals were admitted to inpatient care as a result of their tumoral disease in 2017 (4). Inpatient care in Sweden is provided to those whose medical and/or nursing needs cannot be managed in the outpatient or homecare setting. Inpatient care is often a part of the cancer trajectory. In the oncology setting, there are numerous causes for admission, either acute or planned. In the acute phases, patients are often suffering from side-effects of oncological treatments such as bone marrow suppression, sepsis, nausea, and thromboembolism (5). Acute admissions are also common for patients in later palliative stages, where for example reduced general condition, malnutrition or severe pain require inpatient care. The planned admissions most often involve antitumoral drug treatments such as chemo-, immuno-, or antibody therapies, or radiotherapies (6). Caring for inpatients with cancer is a complex task for all health care professionals involved, that demands advanced medical and nursing skills, as well as excellent communication capacities.

The relationship between in- and outpatient care has shifted during recent years. According to the *Organisation for Economic Co-operation and Development* (OECD), Sweden has the lowest number of inpatient hospital beds (2.3) per 1000 inhabitants in the EU, as well as the shortest average length of hospital stay (5.9 days) (7). The OECD attributes this to more effective primary-, home- and outpatient care, as well as technical advances in surgery making longer hospital admissions unnecessary. In oncology, many treatments previously administered in the inpatient setting are now handled within advanced homecare or at outpatient units. Also, more effective antiemetics and other drugs preventing some of the most serious side-effects replaces previously required hospital admission. The short admissions, in combination with fewer hospital beds and a greater share of patients treated in outpatient setting, result in a selection of more unwell patients with complex treatments in inpatient oncology wards (6).

For the patients and their close ones, an admission to an acute oncology ward can be dramatic and stressful. There are often uncertainties regarding prognosis and outcomes of the hospitalization. Patients staying at the wards have to adhere to certain routines, and maintaining a normal life pattern is usually impossible (8). Often, a hospital admission is characterized both by long hours of waiting and not knowing what's going on (9). It has been described that hospitalized patients find themselves in three types of disadvantages: "institutional", "existential", and "cognitive" (10). The institutional disadvantage concerns suddenly entering, as a patient, the lower level of the hospital's hierarchical organization. The existential disadvantage comes from the physical and mental vulnerabilities that are

associated with failing health. The patients also have a cognitive disadvantage in relation to health care professionals, which can be most evident in inpatient wards if patients are not invited to partake in rounds or plans. The patient role is further emphasized at inpatient ward, as compared to home- or outpatient settings, for example because of the use of hospital clothes, wearing an ID-tag, and the limited privacy (11).

The research on patients' and their close ones' experiences and needs in oncological inpatient settings is sparse. In a survey investigating the certain needs for patients and family members at oncology wards, information and communication needs were, however, rated as most important. To be able to ask questions at any time, and receiving honest and understandable explanations, were the top needs reported by patients and their families (12). In 2018, 144 000 inpatients responded to the Swedish national patient survey about their experiences from staying at a hospital ward. One in five patients reported that they were not adequately involved in decisions regarding their own care, and one in four that they had not received sufficient information during their stay (13). In a large survey among 4020 German patients with cancer, between 38 and 48 % reported unmet information needs regarding treatments and other aspects of the disease (14). Patients admitted to hospital wards are not normally invited to participate in activities such as rounds, handovers, or team conferences, which are situations where care plans are discussed and decided upon. Instead, a common procedure is to inform patients after such activities have taken place, and check if they have questions on what has already been decided (15). Problems with these strategies have been discovered and described since the early days of modern health care. Florence Nightingale highlighted the importance of involving patients in the upcoming plans of care. In her famous "Notes on nursing", she states (16):

You ought to go, we will suppose. Health or duty requires it. Then say so to the patient openly. If you go without his knowing it, and he finds it out, he never will feel secure again that the things which depend upon you will be done when you are away, and in nine cases out of ten he will be right. If you go out without telling him when you will be back, he can take no measures nor precautions as to the things which concern you both, or which you do for him.

Nightingale, Notes on Nursing (1860). Pp 38-39

Without using our terminology, Nightingale refers to the limbo in which an inpatient finds him- or herself, should they not have discussed the plans for the day with the responsible nurse. More recently, initiatives have been taken to promote patients' participation in their health care.

2.2 SHIFT-TO-SHIFT HANDOVERS

A definition of handovers in the health care setting has been given by the Australian Medical Association:

The transfer of responsibility and accountability for some or all aspects of care for a patient, or group of patients, to another person or professional group on temporary or permanent basis (17).

Handovers of the responsibility of patients in the hospital context occur between hospitals, hospitals and primary care, hospitals and home, wards, departments, and shifts. They can take place between health care professionals, or between health care professionals and the patient and/or family members. The focus of this thesis is the handovers that occur between nurses and shifts at inpatient wards, and the term “handover” refers to that activity unless otherwise specified.

Since the beginning of professional inpatient care with employed nurses and physicians, first known in Saint Sampson’s hospital in Constantinople during the 5th century (18), shift handovers have been performed daily in the health care context. Little is known of the earliest handover methods, and while the practice of shift handover is literally ancient, the research field of communication in health care is fairly new. The handover itself has been described as risk-prone procedure where miscommunication can have serious impact on patient safety and continuity of care (19, 20). At the same time, it could function as a possibility to the opposite, and strengthen continuity, patient participation and safety (21).

The literature describes numerous ways of conducting shift-to-shift nursing handover. Responsibility has usually been described as passed on to the next shift by an oral, a recorded, or a written handover, or a combination of these, from one nurse to the next (22, 23). The procedures vary across different contexts and are often characterized by strong traditions and local routines, with little or no substratum in evidence-based practice (24, 25). Nurse-to-nurse communication has been a topic for discussions for decades, and more specifically the core task of handing over responsibility during shift change, for almost as long. It was not until the 1980’s and early 1990’s, however, that the idea of involving patients in this procedure started to gain general interest (26), with increasing attention during the last 10 years.

2.2.1 Bedside handovers

The practice of conducting shift handovers with patient engagement is most often termed 'bedside handover', 'bedside handoff' or 'bedside shift report'. All terms imply the presence of patients, but not to which extent those patients and/or their visitors are expected to participate. The practical details of the bedside handovers vary, but are often regulated by a protocol or checklist for the nurses to follow (27). Such protocols also vary in content, and there is no global standard. In Australia, a SOP was presented in 2008 (28). Several other researchers have followed their example and adapted the SOP to local contexts (29-33). Some models include a safety scan, for promoting patient safety, or to put the emphasis on a joint examination of the patients. Others focus on active patient participation, while some comprise of nurse-to-nurse communication in the vicinity of the patient's bed. It is vital to have disparities in delivery in mind when scrutinizing the literature and describing the consequences of introducing bedside handover models. The studies are evaluating different interventions, despite using the same term.

Not only does delivery vary, but also the incitements for changing to bedside handover. The lack of previous research and significant evidence concerning nurse handovers, in combination with the presumed potential in developing effective models, might have boosted the recent interest for bedside handovers. The idea of involving patients in shift handovers fits with a general endeavor to promote person-centered care with certain focus on communication (34). As described above, surveys among inpatients have repeatedly shown deficits in perceived participation in health care (35), leading to reactions from policy makers in the form of new recommendations for practice (36), and also in changed legal prerequisites in for example Sweden, Finland, the US and the UK. Bedside handovers could potentially be one way of matching demands from patients and decision-makers, given that it truly promotes patient participation. Another commonly stated reason concerns patient safety and complies with the idea that involved patients are safer patients (37, 38). If including a safety scan or similar assessments of safety, bedside handovers could provide with a structured daily check, not necessarily performed when using other handover models (39). This also connects to continuity of care where effective handovers could promote reliable transfer of information (40), which is also supposed to enhance safety and quality of care (41). Lastly, a widespread dissatisfaction with shift handovers among nurses has been reported (24). In an extensive survey, including more than 22 000 European nurses, dissatisfaction with handovers, ranging from 21% in England to 61% in France, was reported (24). The main reasons for not being satisfied were "too many disturbances", "lack of time", and "insufficient information exchange". In summary, lack of evidence, potentially enhanced patient participation, safety and continuity of care, as well as nurse dissatisfaction with shift handovers form the basis for implementing and evaluating bedside handovers.

2.2.1.1 Consequences for patient satisfaction

Patient satisfaction has been increasingly used as an outcome of quality of care and for evaluating various nursing interventions (42), including bedside handovers. Patient satisfaction is commonly defined as a measure of the extent to which patients are content with the health care they receive (43, 44). Patient satisfaction is multi-dimensional, which means that it covers many aspects of the experience of health care. Farley *et al* (45) discuss patient satisfaction as a proxy measure for quality of care and as a basis for hospital reimbursement. The evidence is contradictory, and the authors argue that patient experience in form of patient satisfaction should not necessarily be regarded as a measure of clinical quality. On the other hand, a large review from 2013 investigated the associations between patient experiences and patient safety and clinical effectiveness (46). There were positive associations between higher patient satisfaction and for example greater adherence to medications, health promoting behavior, and less symptoms. Also, associations were shown also between positive patient experiences, and technical quality of care and fewer adverse events. The authors argue that patient satisfaction should be a core pillar of the quality care-concept. Others have taken it further, for example Chow *et al* who mapped the concept of patient satisfaction in the surgical context, and argue that it could represent the ultimate end point to health care quality (47).

An American study used a pre-posttest design, without a control group, to evaluate the implementation of bedside handover in seven medical-surgical wards at a university hospital (48). The study comprised both patient and staff outcomes, including patient satisfaction, collected at three points of measurements with independent groups; pre-implementation (n=233), three months post-implementation (n=157), and at 13 months (n=154). A revised version of the “Patient Views on Nursing Care” scale was used. Overall, patient satisfaction was high at all points of measurement, but improvements could be identified after the introduction of bedside handover. Statistically significant improvements at the 13-month follow-up were found for the items “Made sure I knew who my nurse was” ($p=.012$), “Encouraged to be involved in care” ($p=.005$), “Included in shift report discussion” ($p=.042$), and “Communicated important information from shift to shift” ($p=.027$).

Three studies from the US, investigating patient satisfaction in relation to bedside handovers, have been cited frequently (49-51). The scientific quality of these studies can, however, be discussed. Neither of the studies reported the number of respondents, response rates were low, and in one of the studies no statistical analysis was performed. In addition, no validated questionnaires were used.

In summary, it is often stated as a fact that bedside handovers (or similar models) are associated with increased patient satisfaction. Considering the level of evidence from the studies actually investigating this outcome, the association should not be expressed with such confidence. Patient satisfaction does not appear to be worsened by bedside handovers, but the evidence for improvements is indeed limited.

2.2.1.2 Consequences for patient safety

There is a growing body of evidence supporting the notion that patient participation enhances patient safety (38, 52, 53). Bedside handovers could function as an opportunity for patient involvement in safety issues. Despite the known difficulties in evaluating patient safety, researchers have set out to investigate the handover model's consequences for different aspects of safety.

Several studies have used more objective outcomes for measuring patient safety. For example, the American study, described above, registered and analyzed patient falls, nurse overtime, and medication errors in relation to the introduction of bedside handovers (48). Patient falls during shift change decreased from 20 at baseline, to 13 at the three-month follow-up, and 4 at the 13-month follow up. Nurse overtime remained unchanged, and reported medication errors decreased from 20 at baseline to 10 at the three-month follow-up. In an Australian emergency department, 368 medical records were audited (173 pre- and 195 post-intervention of bedside handover) to examine the completion of nine routine nursing activities, including safety measures (54). The patients were more likely to wear an ID wrist bands (pre: 80.3% post: 94.4%), allergy alerts bands usage increased (pre: 51.2% post: 82%), and documentation concerning IV fluids and cannulas improved, after the introduction of bedside handover. Similar results were presented in a preceding study investigating approximately the same outcomes and intervention (30).

A cross-sectional survey among inpatients at two inpatient medical-surgical wards in the US had the purpose of investigating, among other outcomes, patients' (n=103) perceptions of safety after taking part in bedside handovers (55). The study only included one point of measurement, no baseline data were collected. The relationship between how often patients participated in bedside handovers, and how safe they felt, were analyzed. The authors concluded that the more consistent bedside handovers were performed, the safer patients perceived they were.

An important drawback with all of these studies is the uncertainty regarding which intervention caused the observed benefits. Is it the well-informed patients? The participation

in itself? The structured safety scan during handover? Increased awareness among nurses? As these factors cannot be isolated and tested separately, and the study designs do not allow for cause and effect analyses, it remains unclear what part of bedside handovers that might be effective.

2.2.1.3 Patient experiences of bedside handovers

An inalienable dimension in the evaluation of bedside handovers is the patients' experiences of participating in this traditional nursing task. The measures of patient satisfaction, as described above, hold the advantage of being quantifiable. There is, however, a risk that the items in the questionnaires do not cover the patients' experiences. Therefore, qualitative studies where patients can freely express their experiences are vital for generating hypotheses for further evaluation.

A commonly discussed issue regarding bedside handover is the patients' integrity in relation to co-patients, when cared for in multiple-bed rooms. Nurses often express concerns regarding the disclosure of sensitive information, both when performing bedside handovers(56), and when executing traditional nursing tasks in multiple-bed rooms (57). In an Italian study, 14 patients were interviewed about their experiences from bedside handovers in a cardio-thoracic surgery ward (58). In the semi-structured interview guide, an open-ended question on privacy was included that, via analysis, resulted in the main theme "Experiencing the paradox of confidentiality". While the patients expressed the importance of privacy and how nurses should protect it, none had experienced any unwanted disclosures. Neither had they perceived specific integrity issues related to bedside handover. Instead, several patients were certain that their co-patients were uninterested in their neighbors' handover conversations. In a preceding Australian study with similar design, 10 patients were interviewed on their perspectives regarding bedside handovers (59). Out of these, two participants expressed concerns around integrity, but did not relate them to the bedside handovers, but rather to having to share multiple-bed rooms with patients of the opposite sex. This surprised the authors who expected greater worries from patients in shared rooms in relation to the bedside handovers.

Patient participation is a central issue when the consequences of bedside handovers are discussed. Difficulties in measuring participation through surveys have dispatched these questions primarily to qualitative inquiries, be it interviews or observations. Aspects of participation seem to recur in interviews, even though it remains unclear whether it is brought up by patients spontaneously, or if they only respond to specific questions about participation. In the Australian interview study mentioned above, the authors found three (out of four) themes relating to participation: "Acknowledging patients as partners", "Passive

engagement”, and “Handover as interaction” (59). The interviewees appreciated to be invited to ask questions and to complete the information exchanged by nurses, but saw the constraint time frame (1-3 minutes) as a hinder for further participation. At the same time, the authors of the study described how patients shared a partnership with the nurses during the handovers, and felt like “persons first, patients second”, making the care more personalized. A case study, including observations of 532 bedside handovers, found patients being actively involved in about a third to slightly over half of the handovers (60). Unfortunately, no data on handover duration were recorded. An older interview study investigated patients’ perceptions of participation in bedside handover (26). In the theme “Maintaining professional dominance”, the patients expressed feelings of inferiority when expected to participate during handover, especially when technical and medical issues were discussed. The author related the manners in which nurses provide bedside handover to the bio-medical model in which patients are seen upon as passive objects, and at best receivers of information. In the worst scenario, bedside handover could hamper patient participation when performed in an excluding manner, despite the best intentions (26).

The final, dominating, patient experience from bedside handover, investigated in the literature, concerns information. This can for example relate to the patient being a passive recipient of information, an active seeker of information, or mutual information exchange between nurses and patients. The patient surveys, evaluating bedside handover, usually include questions on information. For example, Scheidenhelm and Reitz, collected questionnaires from 290 patients, 4 months pre-implementation of bedside handover, and from 289 patients 4 months post-implementation (61). The patients were asked to report to which degree they agreed with the statement “Nurses kept you informed”, but no statistically significant improvements from baseline to follow-up were seen. Neither could Sand-Jecklin *et al* (their study was further described above as they investigated patient satisfaction) conclude any improvements on patient outcomes, post-implementation of bedside handover, regarding information in their survey (48).

Even if larger evaluations have failed to show a positive connection between patients’ perceived information and bedside handover, qualitative investigations have demonstrated that patients perceive information benefits from handover participation. The patients interviews by McMurray and co-workers displayed consensus in that bedside handover was an opportunity to gain further information about their medications, and the care plan for the upcoming shift (59). Some patients also believed that it was their role to amend and correct inaccuracies regarding their care during handover. Another interview study described how patients were reassured that relevant information was conveyed during handover, and listened to the nurses’ discussions about their care plan (58). It is notable how both these studies’ results show a low degree of participation in relation to information – a transfer of information from nurses to patients (62), in contrast to information exchange where the

patient provides vital information about his or her condition, preferences, and desires regarding the upcoming shift.

2.2.1.4 Nurses' perspectives regarding bedside handovers

Since bedside handovers concern a core nursing task, and are performed and maintained by nurses, it is inevitable to investigate its consequences for the profession. Just as for the other outcomes, both qualitative and quantitative approaches have been undertaken.

A common measurement is nurse satisfaction with handovers. This was investigated pre- and post-implementation by Sand-Jecklin *et al*, including 300 responding nurses (48). By using a study-specific questionnaire, the nurses assessed different aspects of the handover models. Improvement post-implementation was reported regarding nurse perceptions of efficacy, efficiency, and that handover was less stressful. Scores observed for the statement “the handover takes a reasonable amount of time” deteriorated, indicating that the nurses considered bedside handover to be lengthy. At the same time, nurse overtime did not increase. Other studies have reported decreased nurse overtime with bedside handovers (51). Through a similar pre-test-post-test design, nurse satisfaction of bedside handovers was investigated with a validated instrument (the Bradley Clinical Handover Survey) (63). Improvements were seen overall, but with modest effect sizes. One item stood out and improved most: “The patient is involved in the handover process”, which could reflect a factual statement rather than a positive or negative experience.

Qualitative interviews are common approaches to explore nurses' perspectives of bedside handovers. One of the most cited publications in this field of research is Kerr *et al*'s scrutiny of nurses' and midwives' thoughts on bedside handovers (64). In total, 30 staff members were interviewed 12 months after introduction of the new model. Overall, the nurses perceived that the care provided was of higher quality than before, not the least because of better communication with the patients and their family members, improved documentation, and more efficient work shifts due to the visualization of the patient at the start of the shift. The benefits of early visualization were also emphasized in Chaboyer *et al*'s nurse interviews (60). Just as in the study by Kerr *et al*, these authors also described a perceived strengthened partnership with the patients as a consequence of bedside handover (60, 64). A recurring concern among interviewed nurses in both of these studies were issues relating to integrity, where nurses describe feelings of discomfort while performing bedside handovers in multiple-bed rooms. These concerns were not, however, confirmed by the patients, as shown above (58, 59). Still, nurses describe how they adapt their way of talking – often quieter or avoiding topics they deem as too sensitive.

An Australian discrete choice experiment, using a survey among 200 nurses showed a strong preference for conducting handovers at bedside (65). Despite the described benefits with bedside handovers, as perceived by nurses, managers and researchers have encountered difficulties with the implementation process and more specifically nurse compliance to handover protocols (2, 61). Tobiano *et al* set out to understand the reasons for not maintaining bedside handover among nurses, in a cross-sectional study using a survey (56). Of the participating nurses (n=200), 88 % described barriers, hampering their compliance to bedside handover. Once again, patients' integrity was stressed as inhibiting bedside communication. External interferences, such as alarms, or interrupting colleagues, co-patients or their visitors disturbed communication and made handovers too lengthy. Personal characteristics among nurses and patients were also brought up. Concerning patients, confusion and grave illness were described as hindering communication at bedside. For staff, some nurses expressed distrust in their colleagues' abilities to convey accurate and objective information in front of the patient.

In conclusion, many researchers and clinicians have implemented and evaluated bedside handovers but the evidence remain unclear. A systematic review of the literature from the Cochrane institute aimed at investigating the effectiveness of different nursing handover styles for hospitalized patients (66). It was not possible to include any studies in their formal analysis due to the low quality of study designs, but the review concluded that the involvement of patients in handovers show promising consequences.

2.3 PERSON-CENTERED CARE

2.3.1 What it is

Person-centered care (PCC) is a concept that has gained tremendous attention during recent years. It is often referred to as a way of acknowledging the patient as an equal partner in care (67). This could mean that patients are to be regarded as persons with capabilities, resources, unique needs, and rights (68, 69). Some researchers prefer not to use the term care. Rather, they employ person-centeredness as the relevant concept. In 2017, McCormack and McCance proposed a definition of person-centeredness in their textbook on person-centered practice in nursing (70):

Person-centredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.

McCormack & McCance, Person-centred practice in nursing and health care: theory and practice (2017). Pp 22

In the Swedish context, a commonly referred to, and more practice-oriented definition, is presented by the Centre for Person-Centred Care (GPCC) at Gothenburg University:

Person-centredness is an ethical standpoint that guides our practical actions as fellow human beings and professionals. Person-centred care entails a partnership between patient, their relatives, and professionals, in health and elderly care and rehabilitation. Based on carefully and perceptively listening to the narrative of the patient (often combined with the narratives of their relatives) and other examinations, a health plan is co-created, containing goals and strategies for implementation, along with short and long-term follow-up.

Obtained 2018-12-17 from <https://gpcc.gu.se/english/>.

There are, however, other definitions of PCC, and none of them can be regarded as completely established or universally accepted. This could be either due to the nature of the concept. PCC is depending on the individual's preferences, needs and circumstances, and will therefore vary between persons and contexts. Another possible reason is that PCC still is under development (71).

In concept analyses, researchers have sought to define PCC and distinguish it from similar concepts. In their review of reviews, Sharma *et al* set out to define components of PCC (72). Their overview resulted in six components that recurred in previous descriptions of PCC: 1) To establish a therapeutic relationship, 2) Shared power and responsibility, 3) Getting to know the person, 4) Empowering the person, 5) Trust and respect, and 6) Communication. Morgan and Yoder presented a concept analysis where they describe antecedents, attributes and consequences of PCC and suggestions for measurement/evaluation of PCC in a post-acute health care environment (73). They described a person-centered climate, comprised of antecedents or prerequisites for PCC, as to include vision and commitment, organizational attitudes and shared governance. The attributes of care, characterizing PCC, are holistic, individualized, respectful and empowering. The consequences of PCC were described as to

be found in the dimensions of improved quality of care, increased patient satisfaction, and improved health outcomes. Lor *et al* found similar antecedents, attributes and consequences in their analysis of person-, family- and culture-centered nursing care (74). In summary, even though there are several definitions of PCC, they all focus on the person as the center of health care, rather than the illness or disease.

2.3.2 Person or patient in the handover context

When discussing person-centeredness, the distinction between a *person* and a *patient* needs to be made. In the literature review regarding bedside handovers above, researchers sometimes use the term “patient-centered care” interchangeably with PCC. Despite similarities, however, there are differences regarding these concepts. In a review of concept analyses, Håkansson *et al* conclude that the goals differ between patient- and person-centered care, where patient-centeredness aim at a functional life, and person-centeredness at a meaningful life (75). The philosopher Bengt Kristensson-Uggla summarizes it simply by describing the patient as a “what”, and the person as a “who” (76). Ekman *et al* (68) describe PCC as a shift from a model where the patient is a passive recipient of medical interventions, to one where the patient is acknowledged as a person in the temporary role of a patient. Slater describes how using the term *person* changes the sense of power which lies implicit in the term *patient* or *client* (77). She argues that in acknowledging a person rather than a patient, the right not only to receive care, but to contribute, take responsibility, and share decisions in mutual agreement is emphasized.

In the bedside nurse handover context, this can be illustrated by the purpose of the handovers. It is not primarily to transfer the responsibility of an injured physical object to a colleague (then it would have been relevant with a patient-centered “what”), but to communicate *whom* the colleague will be working with during his or her shift. If the patient takes an active role in the handover, he or she must use the personal capabilities and speak up and communicate thoughts, as a person but in the role of a patient in need of care.

But what is a person? The sociologist Christian Smith argues that human person is an entity and consists of a ‘oneness’, in direct contrast to a reductionist view where we are but a sum of atoms. Meaning, a human being could be described as a composition of various physical parts, uniquely distributed for each person and possible to reduce endlessly (78). It is often argued, however, that this does not give a satisfying answer to what a person is, as there obviously seems to be more to it. Smith means that an emerged entity is always greater than the sum of its parts. This, he explains, is possible because of relationships and that no person lives in a social or environmental vacuum. So, if a person is not only billions and billions of small physical parts, what is it? Smith describes the normal person as:

[...] a conscious, reflexive, embodied, self-transcending center of subjective experience, durable identity, moral commitment and social communication who – as the efficient cause of his or her own responsible actions and interactions – exercises and sustain his or her own incommunicable self in loving relationships with other personal selves and with the nonpersonal world.

Smith, What is a person? (2010). Pp. 61

The term “center of subjective experience” is further described as a philosophical core in every human, where a person’s capacities are gathered and coordinated to create purposeful actions (78).

Kristensson Uggla argues that Smith’s anti-reductionism in the quotation above goes so far that all delimitations are gone and we are left with too vague a definition (76). Instead, Kristensson Uggla highlights Rentoff and Kemp’s four ethical principles that together dynamically create contours of a person: autonomy, integrity, dignity and vulnerability. Rom Harré, on the other hand describes a person as autonomous, distinct and continuous. We are a shifting pattern of unified singularities and multiplicities (79). If we presume that a person is ‘a shifting pattern’, it would mean that our selves are different, depending on context and time and that we relate to our different selves.

A “person” is in all definitions somewhat related to his or her surroundings and contexts, and in some way dependent on others, albeit still autonomous. One could argue that this indeed is the case for a person with cancer, being treated in the inpatient setting. He or she is vulnerable (yet still highly capable) and depending on professionals, not only to receive treatment and care, but also in maintaining dignity and autonomy. Thus, it can be relevant to use the term “person” when describing the handover situation demanding the patient’s participation, as the handover itself occurs when a relationship is established between three or more persons.

2.3.3 The ethics of person-centeredness

Ethics, as a guide for our thoughts and actions, play a central role in all health care settings. It constitutes how we regard patients, how we treat them and the priorities set. The gist in nursing ethics has traditionally been described as dialogical, narrative, relational and contextual. It aims to care for and see to each patient’s needs and ease suffering (80). Ekman, Norberg and Swedberg contrast this ‘need-based’ ethics to one where the patient’s unique resources are emphasized (10).

Paul Ricœur makes a clear distinction between ethics and morals. Ethics is, according to Ricœur “the project of an accomplished life” while morals refer to rules and answer the question “What must I do?” (81). Strongly influenced by Aristotle, Ricœur summarizes his ethics in his model for ethical endeavor: “The goal of a good life with and for others within just institutions” (81). In this maxim, Ricœur three core ethical concepts can be found; the good life (Aristotelian heritage), the relationship with the other, and the need for just institutions.

In an attempt to merge Ricœur’s ethics with traditional ethics in caring sciences, van Nistelrooij *et al* criticize modern health care to focus one-sidedly on illness and physical needs (82). They propose a phenomenological approach, based on Ricœur’s philosophy, where focus is shifted to the experience of being ill and each person’s capacities and unique traits, much similar to the core concepts of PCC described above. Further, the authors emphasize Ricœur’s theories on relationships as a key to overcome one-sidedness, dichotomies (e.g. healthy/sick) and simplifications that they mean influence health care practices. Another interesting and relevant aspect is their contribution to the discussion on the alleged antagonism between ideals and practice. Influenced by Ricœur, they argue for pragmatism and show how good practice can affect ideals and how good ideals can affect practice. This means that the two can be regarded as movements “upwards and downwards”, together shaping and constituting ethics in care (82).

Bedside nurse handovers could highlight a need to focus on ethics and approaches at the same time as changing practice. Ricœur’s thoughts on a person as both capable and vulnerable, as well as his relational theories fit with the aims of involving patients in the nurse handover. One prerequisite for participation in the handover context is that nurses regard the patient as an accountable and capable person, otherwise the procedure will be that of handing over a physical object in need of care.

2.3.4 Participation and partnership

Two commonly recurring terms in the PCC context, as well as the bedside handover context, are *participation* and *partnership*. In her concept analysis of participation in health care, Cahill presents three levels of participation (83). The lowest, most fundamental level concerns patient involvement and/or collaboration. Here, the patient is informed in a one-way manner, and collaborates by agreeing to be a source of medical data needed to perform diagnosis, treatment and nursing tasks. The next level is patient participation where the patient is proactive and information exchange (as opposed to information transfer, as in the

lower level) takes place. The patient is also encouraged to take part in decision-making. Partnership is regarded as the highest level of participation and stands out by its foundation on a mutual agreement between the health care professional and the patient (a deal or a contract). For this to be an ethically defensible contract, according to Cahill, the agreeing parts must be as equal as the care environment allows. Usually this means that a shift of power is needed, where the nurse (or any other health care professional in question) lets go of some power and responsibility as the parts needs to have equal control in a partnership (83).

Regarding bedside nurse handovers, a common incitement for implementation is, as described above, increased patient participation. A goal is often to move upward in Cahill's three-level pyramid of participation. Theoretically, the bedside handover could be an ideal situation for the establishment of a contractual relationship for the upcoming shift.

2.4 PERSON-CENTERED HANDOVERS

The focus of the thesis is the evaluation of person-centered handovers (PCH). PCH are shift-to-shift handovers performed with the patient, the off-going nurse, the on-coming nurse, and sometimes assistant nurses and the patient's visitors. The intention with the PCH in the present thesis was to promote a person-centered, efficient, and safe plan for the upcoming shift and transfer of responsibility, with a certain focus on the patient's priorities. The nurses employed a checklist or guideline to support the practical procedure and to avoid omissions in the information exchange. This checklist is shown in Table 1 and summarizes the intended performance of PCH. Primarily, the procedure was undertaken by the patient's bed, also when the patient rooms were shared. In our setting, PCH were performed only between the morning and the evening shifts around 2PM on weekdays and weekends. More registered nurses than nurse assistants were employed at the wards, hence the assistant nurses could not partake in all handovers. There were no formal restrictions concerning the length of the handover, and the intention was not to reduce handover duration as compared to standard handover (further described below).

The practical development of the PCH model was undertaken primarily inspired by an often-cited SOP (28, 84) for implementing bedside handover in care, and the SBAR (Situation, Background Assessment and Recommendations) communication model (85). The SOP was based on observations of bedside handovers, and interviews with nurses at two Australian hospitals. It was intended to function as supporting material for implementation. The SOP provides a practical guide of how to execute bedside handovers, which activities to undertake and what information to exchange. The authors of the SOP describe five phases of the handover: 1) Preparations, where patients are allocated and informed about the upcoming handover, and patients' visitors other than family members are requested to leave. 2)

Introductions, where the nursing staff greets the patient. 3) Information exchange, where the patients' clinical condition is examined, tests and procedures checked, an update on the discharge plan, and if the oncoming staff has any questions. 4) patient involvement should occur thereafter, where patients are asked to raise questions or to clarify information. 5) Finally, a safety scan is performed according to a checklist, where e.g. the staff checks if the call bell is within reach, that equipment is functioning, and medical and bedside charts are reviewed. This model is clearly centered around the nurses' needs for the upcoming shift in terms of medical information and an update on practical issues regarding the patients. The SOP provided with a clear structure, promoting a safe and comprehensive handover. There was not, however, enough focus on the patient and his/her preferences and information provision to the nursing staff for us to implement it straight off. In the checklist describing PCH (Table 1), we have adapted the overall structure and clarity from the SOP and SBAR, but added more aspects demanding an active patient and changed the order so the handover begins with the patient's own preferences.

2.4.1.1 Bedside handovers or person-centered handovers

As mentioned above, PCH are a type of bedside handovers. The term PCH, however, was chosen because of its certain focus on patient participation and planning of the following shift in cooperation with the patient. Central aspects of PCC, described above, were blended with the practical nursing task of performing shift handovers together with the patient. Foremost, the acknowledgement of the patient as an equal partner in the planning of health care, and as a capable and responsible person, was central in the development of PCH. Thus, the term "bedside handovers" was not regarded as specific enough. "Bedside handovers" only implies the presence of a patient, but not necessarily an actively involved patient. The term PCH was intended to describe the intentions of the intervention more precisely, and better capture its concepts. It is important to remember, however, that the mere appellation of person-centeredness does not guarantee increased patient participation. The true consequences of PCH are not reflected in its term but in its actual delivery to patients.

Table 1. The checklist used by nurses to support PCH. Translated from Swedish.

Person-centered handovers (PCH)

Preparations

- ☐ At approx. 13.15, the nurse assistant informs patients and visitors about the upcoming handover.
- ☐ Assemble at 14:00 for general information from the ward coordinator. Off-going nurses check that patients have been informed and are present.
- ☐ Off-going and on-coming nurses meet up and start the handover in the agreed order. Expect the handovers to last for approximately 10 minute per patient (6 patients≈60 minutes).

At bedside

- ☐ Introduce yourselves and the situation, and greet the patient.
(S, Situation according to SBAR)
- ☐ Start by asking the patient about their current situation and how their day has been
(B, Background according to SBAR)
- ☐ Ask the patient how he/she is doing, and start from his/her viewpoint. Go through relevant aspects of the patients' current status. Remember to involve and ask the patient!
(A, Assessment according to SBAR)
Some keywords could be:

Psychosocial	Circulation	Access	Nutrition	Sleep
Nausea	Elimination	Skin/wounds	Activity	Pain

Patient safety

- ☐ Check the ID-band
- ☐ Risk of falling? (assessment/measures/what does the patient think?)
- ☐ Medications, on-going infusion? Any other equipment that needs to be checked?
- ☐ Changes in medications (Performed? Was the patient involved? Questions about medications?)
- ☐ Does the patient have any concerns regarding his/hersafety? Could be phrased: *"Have you noticed anything new or unexpected today that could affect your safety?"*

- ☐ Recommendations and plans
(R according to SBAR)
 - Upcoming controls e.g. saturation, blood pressure, pulse, wound dressings, fluids, calories. What is planned? When does it suit the patient?
 - Examinations, e.g. x-ray, radiotherapy, preparations? What does the patient know and what are the plans?
- ☐ Make a general plan for the shift. What are the patient's expectations and goals for the next 24 hours?
- ☐ The on-coming nurse recapitulates the handover briefly. Ask for additional input from the patient, and check that there is mutual agreement regarding the plans.

2.4.2 Standard handovers

In the studies included in the thesis, PCH are contrasted to “Standard handovers”. Standard handovers were used at the studied inpatient wards prior to the introduction of PCH. These handovers took approximately one hour when the on-coming nurses began their shift by reading up on their patients in the electronic health records. After the on-coming nurses had read up, an informal oral handover with the off-going nurse often followed. These procedures were performed in a nursing office, secluded from the patients. The standard handovers had no formal structure. Nurses first met the patients approximately 2 hours into their shift. This handover procedure has previously been evaluated in a psychogeriatric setting, showing positive effects on nurse satisfaction (86).

2.4.3 Implementing person-centered handovers

The implementation process of PCH was initiated in 2013 at the Department of Oncology at the Karolinska University Hospital. The context and study design are further described in the “Methods” section of the thesis. A project management group consisting of two nurses with a doctoral degree, three ward managers, and two oncology nurse specialists was formed. The PCH intervention, described above, was developed in cooperation with ward nurses. The implementation strategy was formed by the project management. PCH were to be introduced stepwise at the wards, first at one ward, and then at two more. The same implementation procedures were performed at all wards, but at different time points depending on when PCH were introduced at each ward. First, PCH was introduced to nursing and medical staff by lectures during educational days. The lectures consisted of a review of the evidence concerning bedside handover models, and a thorough presentation of the specific PCH model intended for the Department of Oncology. Educational films were recorded with a professional filming team, depicting the “ideal” example of PCH, as well as less successful examples. After the theoretical education, a role play followed where all nurses and assistant nurses practiced PCH on each other with fictional patient cases. All educational sessions ended with an open discussion on fears, barriers, and facilitating factors regarding PCH. There were also opportunities for nurses to provide feedback on the PCH protocol. Prior to the introduction of PCH, a local project management group was formed at the ward. This group was led by a nurse facilitator (87) and included both enthusiastic nurses, and those who were more skeptical towards PCH. This local group had the main responsibility, together with the ward manager, to maintain and supervise the practical delivery of PCH at the ward. Follow-up meetings were performed regularly during the whole study period with the project management, ward managers, and nursing staff. The implementation process itself was not evaluated in the PCH project.

The literature provides examples of perceived barriers among nurses towards the implementation of models of bedside handovers in inpatient settings. Commonly, concerns

about patients' integrity recur (56, 65, 88), as well as worries about handovers being too lengthy and disrupting the work-flow (28, 56, 89), and hindering individual characteristics of both patients and nurses (56). In the PCH project, the ward nurses expressed similar worries. Each of the perceived barriers were discussed, and follow-up took place during the PCH meetings with staff throughout the study period. The components of the PCH intervention are described in Table 1, and were chosen in collaboration with ward nurses.

No formal use of implementation theory was applied when laying out the strategy. Previous descriptions of implementation strategies for bedside handover models include Lewin's 3-step model for change (2, 28, 90), the Smith and Kaluzny 4-stage change model (19), the Plan-Do-Study-Act framework (91), and the contingency model of Van Linge (92). Without applying a theory in retrospect, the implementation of PCH bears similarities with Lewin's unfreeze (educational sessions, discussions with staff, reviewing evidence for change), change (local project groups, maintenance and audit-feedback), and defreeze (recognizing PCH as the "new standard") model (93).

As previously described, nurse handover practices are often rooted in local, sometimes even ward-specific, traditions. To change an established behavior, and maybe even attitudes regarding the involvement of patients in a nursing activity, is a challenge for any clinician or researcher. A model of bedside handover, such as PCH, fulfills commonly described criteria of a complex intervention. For example, there is variability in possible outcomes, there are many interacting components in PCH, several groups are targeted by PCH (nurses, assistant nurses and patients), and the intervention requires flexibility in its delivery (94). A complex intervention entails certain challenges in both implementation, evaluation and maintenance (94). Four central tasks have been identified as crucial when designing a complex intervention intended to change healthcare professionals' behavior: to identify barriers, to select components of the intervention, to use theory, and to engage end-users (95).

3 AIM

3.1 RATIONALE

Recently, there has been an increased awareness regarding patients' participation in health care. Results from surveys show that patients are not sufficiently involved in decisions and planning regarding their own care. The importance of promoting patient participation through nursing interventions has been widely recognized. Both because of shown beneficial consequences, like improved health outcomes, patient safety, patient satisfaction, and treatment adherence, and the fundamental ethical aspect of each person having the right to take part in decisions and share and receive information concerning their care. Patients treated at inpatient oncology wards can suffer from severe side-effects of treatments, and are often physically and mentally vulnerable. Still, all patients are resourceful persons, and most are capable of taking on a larger responsibility in the planning of their own care, than they are many times allowed. In the current Swedish practice of delivering inpatient care, there is seldom a formalized situation where nurses and patients can discuss the plans. At the same time, the nurses' shift handovers have been described as a risk-prone activity, most often performed secluded from patients, and with little or no base in evidence. Researchers and clinicians have identified the nurse handovers as potential opportunities for involving inpatients in their care. Since about a decade, models of performing the nurse handovers at the patients' bedside have been implemented and evaluated in a range of inpatient settings in Western societies. The evidence is promising regarding patient and nurse reported outcomes, but high-quality studies are scarce.

Person-centered care may contribute to a shift from the traditional biomedical approach where patients were acknowledged as passive recipients of health care, towards being regarded as persons with unique needs, wishes, and capabilities that need to be taken into account when planning and delivering health care.

In an attempt of combining the ethics and core components of person-centered care with the practical task of performing bedside handovers, we developed person-centered handovers. PCH included the patient and possibly his/her visitors, the off-going nurse, the on-coming nurse, and sometimes assistant nurses. PCH were implemented in an oncology inpatient setting. The purposes of the handovers were to promote information exchange between the patients and nurses, to promote an efficient, structured and safe handover, and to provide with an opportunity for creating a joint plan for the upcoming day.

3.2 AIMS

The overarching aim of the thesis was to identify and describe consequences of introducing PCH in oncological inpatient care. The specific aims were:

- To investigate whether PCH could influence patient satisfaction, in comparison to routine handovers (addressed in **Paper I** and **III**).
- To investigate if PCH could affect information provision, as perceived by patients (**Paper IV**).
- To evaluate PCH's possible consequences on other patient reported outcomes of interest, such as individualized care (**Paper III**), HRQoL (**Paper IV**), and aspects of information exchange and patient safety (thesis summary chapter).
- To describe registered nurses' perceptions of working with PCH in the oncology inpatient setting (**Paper II**).

4 METHODS

4.1 DESIGNS

The thesis is based on three different studies, resulting in four papers. An overview of the designs and outcomes of the four papers is presented in Table 2.

Table 2. Overview of the included papers in the thesis.

	Paper I	Paper II	Paper III	Paper IV
Design	Cross-sectional study with two points of measurement	Qualitative interview study	Cross-sectional study with one point of measurement	Cross-sectional study with two points of measurement
Participants	Oncological inpatients	Registered nurses	Oncological inpatients	Oncological inpatients
Study period	Prior to and after the introduction of PCH	Two years after the introduction of PCH	Two years after the introduction of PCH	Prior to and after the introduction of PCH
Outcome	Patient satisfaction	Nurses' perceptions	Patient satisfaction, Individualized care	Information provision HRQoL
Measures	EORTCIN-PATSAT32	Semi-structured interviews	EORTCIN-PATSAT32 ICS	EORTCQLQ-INFO25 EORTCQLQ-C30
Analysis	Uni- and multivariable linear regression	Qualitative content analysis	Uni- and multivariable linear regression	Uni- and multivariable linear regression

Paper I and **IV** emerged from the same study with a cross-sectional design with two points of measurement. **Paper III** had a similar cross-sectional design as the first study, but with one point of measurement. A study-specific questionnaire was used in both of these studies, but was not presented in the manuscripts. The results are shown in the result section of the thesis. The third study had a qualitative design and included registered nurses as participants. The variation of study designs and approaches aimed at describing and evaluating PCH as

soundly as possible under the clinical circumstances. The idea was to achieve a comprehensive understanding of PCH in the specific oncology context by combining qualitative and quantitative methods (96).

4.2 CONTEXT

The development, implementation and evaluation of PCH took place between 2013 and 2018 at the Department of Oncology at the Karolinska University Hospital in Stockholm. During that time, the department had four inpatient wards, located at two different hospital sites. Three of the wards were in the same building, while the other ward was located at another hospital site in a different part of Stockholm. Only the first three wards were involved in the studies described in this thesis. The three wards cared for adult patients with cancer. Patients were admitted from the hospital's general emergency department, from the Oncology department's own emergency room, or from home in case of elective admissions. The wards had different specializations where one ward primarily treated patients with breast cancer, gynecological cancer or sarcoma, one ward specialized in patients with urological- or gastrointestinal cancer. The third ward had patients with head- and neck- or lung cancer. There was, however, a substantial overlap regarding diagnoses between the wards during the study period.

The wards had single-, double- and four- bed rooms. Men and women could share rooms. All wards had one dining room/living room for the patients and their visitors to use whenever they wanted. There were usually no rooms assigned for private conversations. Most often, the ward rounds with physicians and nurses occurred in the mornings, while the nurse handovers took place around 2 PM. Patients were allowed to have visitors between 1 PM and 7 PM.

The wards employed registered nurses with or without specialist degrees in oncology nursing, assistant nurses and secretaries. Physicians, physiotherapists, occupational therapists and dieticians also worked at the wards. During the study period, management shifted on all wards as well as for the Oncology department. There was also a significant nurse turnover in connection to financial cuts and changes in management. These circumstances led to the shutdown of one ward during the study period (September 2015), and a vast reduction in hospital beds at the other two. Also, nurse agency staff constituted a larger share of the nursing workforce following the financial reduction.

4.3 PARTICIPANTS AND DATA COLLECTION

4.3.1 Paper I, III and IV

Patients who were 18 years or older, diagnosed with cancer, stayed for at least three days at any of the inpatient wards, and understood Swedish, were eligible for participation. Patients who were in a terminal stage of cancer or cognitively impaired were not asked to participate.

The three-day stay criterion was chosen for two main reasons. Firstly, the patients should have had sufficient experience of PCH before evaluating them, and three days seemed like a reasonable amount of time. The average length of stay per admission, at inpatient wards for adults with tumoral diseases, was 6.65 days in Sweden 2017 (97). Thus, we expected to avoid too much of a selection bias in relation to length of stay. Secondly, the main endpoint of the data collections concerned patient satisfaction and we used the instrument EORTC IN-PATSAT32 (further described in the “Outcomes and instruments” section below). This particular questionnaire was developed with patients with cancer who had spent three days or more at an inpatient ward (98).

The inclusion of patients in the first study (**Paper I and IV**) was performed by ward nurses but coordinated by the project management. All patients who were planned for discharge from the wards during the study period were screened for inclusion by the ward’s nurse coordinator to enable a consecutive sample and avoid selection bias (96). The nurse coordinator used a checklist to determine whether the patients fit the inclusion criteria and consulted the ward nurse in case of uncertainty regarding the patient’s physical or cognitive status. If the patient was eligible for inclusion, the nurse responsible for the discharge gave oral information about the study and handed over the questionnaires with written information. The patients were asked to fill out the questionnaires at home and then use the prepaid envelope to mail their responses to the project leader. A returned questionnaire was regarded as informed consent to participate in the study. If no response had arrived within one week, a reminder with new questionnaires was sent to the patient’s home address. A non-response or a returned blank questionnaire was regarded as declined participation. For the participating patients, a note was registered in their electronic health records to avoid double inclusion in case of readmission to the wards. The remaining background data on participating patients were collected via their electronic health records.

Even though the inclusion criteria were the same for patients in the second study (**Paper III**), a different approach regarding the data collection procedures was employed. This study was carried out after the financial downsizing and the shutdown of the previous intervention ward (described above). It was not considered reasonable to further burden the nurses, still employed at the wards, with another data collection. Instead, I screened patients for inclusion

every weekday via the electronic health records and identified those who fulfilled the inclusion criteria in collaboration with the responsible ward nurses. I met the eligible patients in their rooms and gave oral and written information about the study. In contrast to the procedure for the first study, inclusion did not have to be related to the patient's discharge, and participants often chose to respond to the questionnaires immediately or sometime during the rest of their stay. The patients who responded at home sent their questionnaires to me with regular mail in a prepaid envelope. No reminders were sent to the non-responders. Background data were collected from the electronic health records only for patients who chose to respond and thus had given their informed consent.

The decision to not collect background variables on non-responders was taken to respect the integrity of those. This decision came at the cost of not being able to perform comparisons between responders and non-responders.

4.3.2 Paper II

This study had a qualitative design and the population of interest was registered nurses employed at the inpatient wards. Nurses who had worked at any of the three inpatient wards for at least six months prior to inclusion were asked for participation. Nurses who worked night-shifts only were excluded, as PCH were not employed at night time. The study period ranged from December 2016 to June 2017, and 13 nurses fulfilled the inclusion criteria. Of these, 11 chose to participate.

The minimum of six-month working experience was chosen to exclude nurses who had just recently been employed, as well as the agency staff nurses hired at the time. It is reasonable that participants who are asked to evaluate interventions should have adequate and sufficient experience of the phenomena in question (96, 99). Six months employment was thus decided as a minimum to ensure experience of PCH. This might have resulted in fewer participants but, on the other hand, these provided rich data which gave valuable information related to the study's aim.

Eligible nurses were identified via the nurse managers at the wards and received written information about the study, either by email or by a note in their lockers. They were contacted a few days later in person by me, who gave further oral information about the study and asked for participation. If the nurse wished to participate, a time and place with the interviewer (co-author Oili Dahl (OD) was decided upon. OD is a registered nurse with a PhD degree and independent of the PCH project. She had no prior relationships to the study participants. The interviews took place in a room at the department, but outside of the

inpatient wards. The interviews were recorded and the sound files were handed to me for transcription and analysis.

The interviews were based on a guide with five open-ended questions. The questions were focused on descriptions of experiences and perceptions of working with PCH, how nurses regarded the patients' role during PCH, and their thoughts on the role of patients' visitors during PCH. The nurses were also asked to describe if and how their caring relationship with the patients was affected by PCH. Finally, they were asked about suggestions regarding the development of PCH. The interview guide aimed at facilitating an open conversation, where the nurses felt free to bring up any issues they found relevant related to PCH, but still focusing on the topic at hand. The study had an inductive approach. The development of the interview guide was inspired by previous qualitative publications where nurses were interviewed on their perceptions of bedside handovers. Bruton *et al* (100) asked nurses to describe the structure of handovers and how they performed it, about their perceptions on the handovers' purpose, and the patients' and family members' roles during handovers. A more practice-oriented approach was shown by Chaboyer *et al* (60) in their interviews where nurses were to describe how they ensured patient participation, accuracy, privacy, their preparations for bedside handovers, and if there were any variations in performance. A similar guide with the same question areas was used by McMurray *et al* (28). Kvale and Brinkmann (101) describe that when formulating an interview guide, the questions should function both thematically and dynamically. The thematical dimension of a question relates to what kind of information is sought after, and how that information can be used in the analysis of the interview. The dynamical dimension refers to how the question stimulates conversation and a positive interaction between the interviewer and the informant. An effective research question should cover both dimensions (101). The interview guide used in the study was developed by the co-authors with these dimensions in mind, topics used in previous similar studies, and the overall aim of the study.

4.4 OUTCOMES AND INSTRUMENTS

4.4.1 Patient satisfaction (Paper I and III)

The main endpoint for the PCH project was patient satisfaction. To evaluate patient satisfaction, the *European Organization for Research and Treatment of Cancer* (EORTC) IN-PATSAT32 instrument was used. The instrument was developed in the early 2000's, with the purpose of measuring patient satisfaction among oncological inpatients (98). The EORTC IN-PATSAT32 is comprised of 32 items, which are compiled into 11 multi-item scales and 3 single-item scales. The scales are: doctors' and nurses' technical skills (DTS: 3 items and NTS: 3 items), interpersonal skills (DIS: 3 items and NIS: 3 items), information provision (DIP: 3 items and NIP: 3 items) and availability (DAV: 2 items and NAV: 2 items); other hospital staff's interpersonal skills and information provision (OTH: 3 items), exchange of

information (EXE: 1 item) and waiting time (WAI: 2 items); hospital accessibility (ACC: 2 items), comfort (COM: 1 item) and general satisfaction (GEN: 1 item) (102). The response format for all items is a 5-point scale ranging from 1 (“Insufficient”) to 5 (“Excellent”). The time-frame of the questionnaire is the most recent admission.

The instrument has been tested for reliability and validity in a large analysis of its psychometric properties (98). Regarding reliability, the scale internal consistency and reproducibility were assessed. Internal consistency is a measure of how well the different scales reflect the same concept, in this case patient satisfaction, often calculated with an estimation of intercorrelation between the scales (103). The internal consistency of the scales in the EORTC IN-PATSAT32 was “good to excellent” with a range of Cronbach’s alpha coefficients from 0.80 to 0.96 (98, 103). Reproducibility was calculated with a test-retest procedure, where differences in ratings were assessed between the first and second point of measurement. The smaller the differences, the better the reliability (103). For the EORTC IN-PATSAT32, reproducibility was acceptable and the intrascale differences were small (97). In the same study, the instrument’s validity (what is being measured (103)) was evaluated by comparing responses from the EORTC IN-PATSAT32 with Oberst patient’s perception of care quality and satisfaction scales, and with the EORTC QLQ-C30, as well as by comparing responses between groups of patients that were expected to rate patient satisfaction differently. The correlations between the EORTC IN-PATSAT32 responses and the Oberst questionnaire were moderate, and correlations with the EORTC QLQ-C30 were not significant, indicating divergent and construct validity (103). The instrument was able to discriminate between patients who differed in care expectations, but not between patients with different age or educational level (98). A recent review of the measurement properties of the instrument confirmed test-retest reliability and construct validity, but could not establish conclusions on internal consistency (104).

4.4.2 Perceived information (Paper IV)

Information received, as perceived by patients, was used as an endpoint in **Paper IV**. This was measured with the EORTC QLQ-INFO25 questionnaire, which is a 25-item module to the HRQoL questionnaire EORTC QLQ-C30 (105, 106). The items focus on the quantity of information that respondents perceive they have received, rather than satisfaction with or quality of information. The questionnaire contains four multi-item scales (Information about the disease, 4 items; Information about medical tests, 3 items; Information about treatments, 6 items; Information about other services, 4 items), and 8 single-item scales (Information about different places of care; Information about things you can do to help yourself, Written information, Information on CD tape/video, Satisfaction with the information received, Wish to receive more information, Wish you have received less information, Overall the information has been helpful). Responses range from 1 (“Not at all”) to 4 (“Very much”), and

“Yes” or “No” for four items. The time frame of the questionnaire is the patients’ whole disease or treatment period.

The EORTC QLQ-INFO25 was validated in an international study including 509 patients with cancer (105). Divergent validity in relation to the core questionnaire EORTC QLQ-C30 was established, as well as the scales’ internal consistency and test-retest reliability. Convergent validity was also confirmed when investigating related scales of the EORTC IN-PATSAT32 questionnaire.

4.4.3 Health related quality of life (Paper IV)

In **Paper IV**, HRQoL was evaluated together with perceived information, among the patients. The EORTC Quality of Life Core Questionnaire (QLQ-C30) version 3 is a cancer-specific questionnaire consisting of 30 items. It contains functional scales, symptom scales as well as individual items, covering aspects of HRQoL for patients with cancer. Five functional scales concern physical-, role-, emotional-, cognitive-, and social functioning. Three multi-item symptom scales assess fatigue, pain, and nausea and vomiting. In addition, five single items concerning common symptoms or side-effects are included (dyspnea, loss of appetite, constipation, insomnia, and diarrhea), as well as one item on financial impact of the disease. These items’ responses are all scored with 4-point scales ranging from 1 (“Not at all”) to 4 (“Very much”). In addition, there is one multi-item scale concerning global health status and overall quality of life (2 items). For this scale, responses range from 1 (“Very poor”) to 7 (“Excellent”). The time frame of the questionnaire is “during the previous week”.

The EORTC QLQ-C30 has been widely used in cancer settings and clinical trials since the 1990’s when it was first developed (107). A multitude of validity and reliability studies have been performed. Osoba *et al* (108) investigated several psychometric properties of the instrument among 535 patients and found, among other aspects, strong intra-scale correlations and good sensitivity regarding symptom burden. Fossa *et al* (109) showed high test/retest reliability for both the functional scales and the symptom scales. The Swedish version of the older core instrument (EORTC QLQ-C36) has also shown overall validity (110). There is also reference data from the Swedish population for the EORTC QLQ-C30 (111).

4.4.4 Individualized care (Paper III)

A secondary endpoint in the second study (**Paper III**) was patients’ perceptions of individualized care. Individualized care relates to the hospital staff’s abilities to respond to

the patient's needs and wishes, and has been described as a central dimension of person-centered care (112). Thus, the Individualized Care Scale (ICS) was used. The ICS for patients was developed by Suhonen *et al* (113) in the early 2000's and is divided in two parts, the ICS-A and the ICS-B. The ICS-A is intended to measure the practice of individualized care from nursing intervention, i.e. what was done by nurses to promote individualization in care. The ICS-B, covers questions on how individuality of care was perceived by the patients, i.e. how the nursing interventions were perceived. The two parts consist of 17 items each, covering the same subscales: "Clinical situation" (7 items), "Personal life situation" (4 items), and "Decisional control over care" (6 items). The response format is a 5-point scale ranging from "Do not agree at all" to "Agrees completely", and the questionnaire's time frame is the most recent admission.

The ICS has been tested in inpatient cancer settings, in Sweden and elsewhere (114, 115) and seems to be cross-culturally comparable with other Western European countries (116, 117). It has also proved construct validity (115), convergent validity, and internal consistency (118). The ICS has also been acknowledged as one of the four most common tools for the measurement of holistic person-centered care (119, 120).

In the second study, the ICS was introduced as a new questionnaire within the PCH project. It had not been used before in the current setting, or to our knowledge to evaluate a bedside handover model. Therefore, there were no previous data to compare our results with. The intention from the design phase of the second study was to include the ICS-nurse version and to compare the perceptions and experiences of individualized care between nurses and patients, which would promote a better understanding of the concept (121). The ICS was also intended to function as a baseline for further evaluations of individualized care at the department. Unfortunately, the staff turnover at the time of the study made the measurement with ICS-nurse all too challenging. There was also a risk for a biased result considering the financial situation, affecting the nurses' workload and turbulence in management.

4.4.5 Study specific questionnaire (thesis summary chapter)

A study-specific questionnaire was added for the participating patients to respond to in studies of patients' perceptions of PCH. The questionnaire was first developed for a study preceding the PCH project at the department (1), and was later shortened and adapted to supplement the instruments described above. The 15 questions remaining after adaption are presented in Table 4, in the Results section of the thesis. The purpose of the questionnaire was to include items on participation, patient safety issues, integrity, and information exchange, as specific as possible for PCH in the inpatient setting. It has not undergone any formal psychometric testing, but was developed by the researchers involved in the PCH

project. Responses range from 1 “Not at all” to 4 “A lot”, and three items have “Yes” or “No” options. The time frame of the questionnaire is the most recent admission to the Department of Oncology.

4.5 DATA ANALYSES

4.5.1 Paper I, III and IV

The statistical analyses were performed in Stata for Windows (version 14, Stata LLC, College Station, TX, USA) and Stata for macOS (version 14).

4.5.1.1 *The first study (Paper I and IV)*

One inpatient ward (I) constituted the Intervention group, while two wards (C1 and C2) formed the Comparison group. The studies had a cross-sectional pre-posttest design, with two points of measurement (T0 as baseline and T1 as follow-up). The groups were independent, meaning patients could only respond once. Thus, the patients included at T0 were not the same as those responding at T1.

For analysis of the EORTC IN-PATSAT32, the 1-5-point responses were linearly transformed into a 0-100 scale, where a higher number indicated greater satisfaction. Mean values were calculated for each scale of the instrument for patients from the three wards at both points of measurement respectively, and presented as means with standard deviations. The mean differences between the intervention ward and the comparison wards on regarding the scales were calculated at T0 and T1 respectively, with a linear regression model. Differences were presented with unadjusted p-values ($\alpha=5\%$), and adjusted with a multivariable regression including patients' sex, age (continuous), educational level (compulsory school/upper secondary school/university), and treatment intention (palliative/curative).

In **Paper IV**, the EORTC QLQ-INFO25 and the EORTC QLQ-C30 questionnaires were used at T0 and T1. The 1-4 responses were linearly transformed to a 0-100 scale (122). For the EORTC QLQ-INFO25, higher scores represented larger amounts of information received, or higher satisfaction with information. Regarding the EORTC QLQ-C30, higher scores on the functional scales, global health/overall quality of life scale reflect higher levels of functioning, while higher levels on the symptom scales means higher levels of symptoms or problems burden. For both instruments, scale mean scores were calculated and compared between the Intervention ward and the Comparison wards at T0 and at T1 respectively. In **Paper IV**, the two Comparison wards were merged into one group. The comparisons

between mean differences in information provision and HRQoL were calculated with a linear regression model, both unadjusted and adjusted for sex, age, educational level, and treatment intention. α was set to 5%. Categorical responses (the 4 “Yes” or “No” items in the EORTC QLQ-INFO25) were compared with χ^2 tests.

Clinical variables collected in the first study were presented with descriptive statistics. Comparisons between the Intervention ward and the Comparison wards were performed with Mann-Whitney tests for continuous variables, comparisons for categorical variables were performed with χ^2 tests. In **Paper IV**, the clinical variables of the participating patients were presented with descriptive statistics only.

4.5.1.2 Sample size calculation (Paper I and IV)

Paper I and **IV** stem from the same data collection and thus the same sample size calculation. The required number of participants was estimated based on the main endpoint, patient satisfaction, and more specifically the scale “Exchange of information between caregivers (EXE)” in the EORTC IN-PATSAT32. In the large validation study from 2005 (98), the mean score of “EXE” was 65 with a standard deviation of 25. If the same levels were assumed for the patients at the Comparison wards, 200 patients (100 at the Intervention ward and 50 each from the Comparison wards) would yield a power of 80% to find a true mean difference of 10 units at T1 between the wards, with an α of 5%. The expected range of a 95% confidence interval would be ± 7 units. For the baseline measurements, 100 patients (25 from each of the comparison wards and 50 from the intervention ward) were needed to compare patient characteristics. In total, the sample size was set to 300 patients.

4.5.1.3 The second study (Paper III)

The calculations of patient satisfaction were carried out in the same way as in the first study, following the guidelines for analyzing the EORTC IN-PATSAT32 scale. The second study, when PCH had been implemented at both wards, had one point of measurement. Patient satisfaction mean scores were compared with the corresponding data from the Comparison wards at T1 in the first study. Comparisons were performed with linear regression. Both unadjusted and adjusted analyses were made. The differences in the multivariable adjusted regression were controlled for age, sex, and treatment intention. Just as for the first study, the level of significance was set to 5%.

The ICS was analyzed according to recommendations by the researchers who developed the instrument (113). Mean values were calculated for the ICS-A and ICS-B, as well as for their

respective subscales. Each scale yields a value between 1 and 5, where higher scores reflect greater support for individualization through nursing interventions (ICS-A) or higher degree of perceived individuality in care (ICS-B). The results were presented as mean scores with 95% confidence intervals.

The background variables from the participating patients in the second study were presented with descriptive statistics only. No statistical comparisons with patients from previous measurements were performed.

4.5.1.4 Sample size calculation (Paper III)

Just as in the first study, the main endpoint was patient satisfaction and the subscale “Exchange of information between caregivers (EXE)” in the EORTC IN-PATSAT32 questionnaire. In the pilot study, carried out at the same wards, preceding the PCH project (1) the mean score of “EXE” was 62.8 with a standard deviation of 23.4 among the 104 participants. A sample of 100 patients in **Paper III** would have a power ($1-\beta$) of 80% to detect a true mean difference of 7.5 units between patients from the previous measurements and from the present study, using a significance level (α) of 5%. With a sample size of this magnitude, the 95% confidence interval for the estimated scale mean of “EXE” would be in order of ± 5 units. Thus, the desired sample size of **Paper III** was 100 patients from the two included wards.

4.5.2 Missing data

Missing data can refer to either missing items, or missing questionnaires. In **Paper I, III** and **IV**, a missing questionnaire was regarded as non-response, and these patients were not included in the analyses. There were, however, missing responses in the returned questionnaires. For the EORTC questionnaires, those were treated according to the scoring manual of the EORTC QLQ-C30 (122). For multi-item scales, if at least half of the included items were answered, the missing items were assumed to have equal values to those in the same scale who were answered for that patient. For single-item scores, a non-response was regarded as missing and no imputation was performed.

For the ICS, no imputation was performed. If more than 20% of items in any of the scales were missing, the scale from that patient was excluded from analysis (123).

4.5.3 Analysis of the study-specific questionnaire (thesis summary chapter)

The new data presented in the thesis summary chapter emerge from the study-specific questionnaire described above and were not included in any of papers in the thesis. The options “Quite a bit” and “A lot/yes” were compiled to “Satisfied” for the items 1, 2, 3, 4, 6, 8, 9, 10, 12, and 13. For the items 5, 7, and 11, the options “Not at all/no” and “A little” were compiled to “Satisfied”. The questionnaire generated ordinal data where response levels could be ranked, but the differences between them were not possible to quantify (96). The only analyses performed were χ^2 tests where distributions between “Satisfied” and “Not satisfied” (or “Yes” and “No” for questions 14 and 15) among the groups were compared. No specific sample size calculation was performed for the study specific questionnaire, instead it was added to the data collections in **Paper I, III and IV**.

4.5.4 Data analyses in the qualitative study (Paper II)

The aim was to include all nurses who fulfilled the inclusion criteria. The transcribed interviews were analyzed with inductive content analysis, according to Elo and Kyngäs’ description (124). An inductive approach was chosen over deduction because of the limited evidence presented in previous studies on the topic of interest. Thus, there was no obvious theory or framework to fit (125). Elo and Kyngäs describe the analytic process as a three-step procedure: the preparation phase, organization phase, and reporting the results. In this section, the procedures of the first two phases are presented.

4.5.4.1 Preparation

Firstly, the whole interviews were decided to form the units of analysis. Graneheim and Lundman recommend each interview to be regarded as a unit of analysis, being short enough to grasp, but rich enough to provide with wholeness (126). It was also decided that the manifest content only was to be analyzed (i.e. what could be seen in the text). During the preparation phase, the researcher should make sense of the data and get a general understanding “of the whole” (124). I read all interviews several times to become familiar with the content, and to prepare for coding and categorization.

4.5.4.2 Organization

After the initial preparations of the material, the data were to be broken down into smaller units. I identified meaning units in the text. The meaning units consisted of either single words, whole sentences, or even paragraphs, that carried a single message responding to the study’s aim. Some of the meaning units were condensed into shorter descriptions to facilitate further categorization. All meaning units were coded, which meant they were “tagged” depending on their message. This coding process concentrated the material into a manageable

amount of data. The codes were clustered and roughly thematized into several higher order captions, which were collapsed or separated. This stage of the analysis involved interpretation as to decide which codes and themes belonged together, and required careful comparison and assessment. The main themes were separated with sub-themes to capture and describe the variety of content within the themes. Elo and Kyngäs describe how inductive content analysis form categories rather than themes (124). Categories are often described as mutually exclusive, whereas themes allow overlapping content to some extent (127). Hence, the groups of data are named themes and subthemes because of their partly overlapping content. The initial analyses were performed by me and MB, independently of each other, and later discussed until consensus was reached. YB then compared the interviews with the thematization and discussed uncertainties and vague appellations with me and MB until a final result was agreed upon.

5 ETHICAL CONSIDERATIONS

All studies included in the thesis have received ethical approval, including amendments, from the Regional Ethical Review Board in Stockholm. The first study was approved in 2013 (ref 2013/1378-31/2). The second study was conducted after an approved amendment to that application (ref 2016/1326-32). A separate application was approved for the qualitative study (ref 2017/750-31/2).

The studies included in the thesis all involve human beings, which entails certain rules of conduct. The Declaration of Helsinki provides general ethical principles regarding medical research, most focused on the well-being of the research subjects (128). A more comprehensive set of standards, involving the Swedish legally binding regulations, was presented in 2017 by the Swedish Research Council (129). Although the law stipulates that all research on humans must be approved by ethical boards, there are numerous aspects of ethical importance that are not covered by legal texts. For the studies included in this thesis, I have summarized a few further points of discussion regarding central ethical issues.

First of all, two of the studies included patient reported information as their primary endpoints. All of these patients had a cancer diagnosis and were treated for cancer-related problems at an inpatient ward. Regardless of their diagnosis or stage of cancer, they were all physically ill in that current situation, and therefore potentially vulnerable. We were careful when considering inclusion criteria and did not want to burden those who were in a terminal stage of cancer. In the written and oral information to the participants that preceded all inclusion, voluntariness was emphasized, meaning that decline of participation was possible at any time without compromising their care or treatment. It was also stated in the information, that not wanting to participate did not render any negative or positive consequences. Still, it is possible that patients felt more of a pressure to participate, especially in the first, since the oral information about the study was given by their nurse. This procedure might also have caused uncertainty among the patients concerning accessibility to the completed questionnaires, and whether answers could affect their care. To avoid social desirability and reluctance to participation, the issues on confidentiality were pinpointed in the written information sheet. We cannot, however, be certain that patients were not affected by social desirability at the moment of considering consent. In the second study, we chose a different procedure where I approached the patients who fulfilled the inclusion criteria. I was not involved in their care, and introduced myself as a PhD student, working at Karolinska Institutet. Hopefully, this reduced potential reluctance to decline participation.

In all four papers included in the thesis, sensitive personal data from the participants were gathered. Protecting confidentiality was therefore central. For patients this included data on,

for example, diagnosis, treatment intention, and opinions about their received care. The nurses who were interviewed shared personal, and possibly confidential, experiences that we recorded and transcribed. All participants, both patients and nurses, were assigned a study-specific ID number that was printed on the questionnaires and replaced the names in the interview transcripts. Only the researchers directly involved in the project have access to the key connecting ID numbers to individual study participants. All results are presented in ways that make it impossible to identify individual participants.

Another important ethical discussion regards the PCH intervention itself, both in relation to the studies, and in general. Regarding the studies, PCH is not a conventional research intervention where the prospective study participants receive information and then decide whether they should be exposed or not (or randomized to either arm). Instead, exposure to the intervention preceded information about the study. Thus, the informed consent to participate regarded the evaluation of PCH, and not the exposure to it. Of course, patients could always decline participation in PCH at the wards, just as with any other nursing interaction. Still, participation was presupposed and patients could not choose to be cared for at a different ward, not employing PCH. Such a procedure demands careful consideration and a risk-benefit assessment (96). In the literature review preceding the development of PCH, no negative consequences of bedside handovers were described. On the other hand, we found no studies that actually investigated e.g. dissatisfaction with care. The sole concern described regarded patients' integrity in relation to handovers, further described in the background section of the thesis. In previous studies, integrity issues seem to be primarily brought up by nurses rather than patients. Malfait *et al* (88) provides an interesting discussion paper on the topic where they describe how nurses sometimes use patients' integrity as an excuse not to perform bedside handovers, instead of taking measures to minimize the breach of patients' privacy. The authors argue that patients' need for information is more important than integrity, especially considering that bedside handovers do not impair privacy more than other nursing activities performed daily at an inpatient ward. Considering that the possible benefits of PCH could be many, and the possible drawbacks few, we considered it to be reasonable from an ethical perspective to expose patients to PCH and to evaluate the consequences.

6 RESULTS

6.1 PARTICIPANTS

The studies included in the thesis are based on data reported by both patients and registered nurses. A summary of the background characteristics of the participants in **Paper I** and **IV**, **Paper II** and **Paper III** is presented in Table 3. For **Paper I, III** and **IV**, a total of 694 patients were asked to evaluate their care. During the baseline measurements of the first study (January 2014-May 2014), 116 patients (58 %) completed the questionnaires. A total of 209 (61 %) responded at the follow-up assessment (September 2014-May 2015). The data collection in the second study (September 2017-March 2018) included a total of 90 patients (75 %). Regarding the registered nurses, 11 out of the 13 who were eligible for participation agreed to be interviewed.

Table 3. Overview of participants in Paper I-IV. Participants in Paper I, III and IV were patients, while Study II was based on registered nurses.

	Paper I+IV	Paper III	Paper II
Number of participants	325	90	11
Age, mean	65	64	39
Age, range	25-90	18-83	23-60
Sex, n (%)			
Female	180 (55)	53 (58)	11
Male	141 (43)	37 (42)	--
Missing	4 (1)	--	--
Treatment intention, n (%)			
Curative	136 (42)	17 (19)	--
Palliative	180 (55)	73 (81)	--
Unclear	9 (3)	--	--
Education, n (%)			
Compulsory school	75 (23)	--	--
Upper secondary school	83 (26)	--	--
University degree	160 (49)	--	--
Missing	7 (2)	--	--
Admission, n (%)			
Acute	237 (73)	--	--
Elective	84 (26)	--	--
Missing	4 (1)	--	--
Length of stay, mean number of days	7	--	--
Oncology nurse specialist, n	--	--	4
Work experience as registered nurse, mean years (range)	--	--	10 (1-30)

6.2 PATIENT SATISFACTION

Patient satisfaction was assessed at three points of measurement within the first and second study. In the first study 1) at baseline (T0) among 113 patients from the three included wards, and 2) at T1 among 209 patients. Of these, 105 had been exposed to PCH and were cared for at the Intervention ward. In the second study 3) at T2, 90 patients who had been cared for at the previous Comparison wards assessed their care, after being exposed to PCH.

6.2.1 Paper I

There were no statistically significant differences regarding the mean scores of the EORTC IN-PATSAT32 subscales between the Intervention ward and the Comparison wards at baseline, neither in the crude comparison, nor in the comparison adjusted for age, sex, education and treatment intention. At T1, after PCH had been introduced at the Intervention ward, only one scale, “Exchange of information between caregivers (EXE)” showed a statistically significant improvement in the Intervention ward as compared to the mean score of the Comparison wards (a mean difference of 12 units). The result was maintained in the adjusted analysis, indicating that none of the chosen covariables could explain the observed differences. No other differences between the wards were found for the IN-PATSAT32 subscales after implementation of PCH.

6.2.2 Paper III

The second evaluation was carried out two years after the first at the previous Comparison wards. PCH had been implemented and maintained for a longer time at the wards, and was thus considered to be established. The patient satisfaction scores collected in the second study were compared to those from the same wards at T1 in the first study. Of all the subscales, two (“Exchange of information between caregivers” and “Nurses’ information provision”) showed a statistically significant improvement at T2 compared to T1, both in the unadjusted and in the adjusted comparison. The mean difference for “Exchange of information between caregivers” was 15. The corresponding figure for “Nurses’ information provision” was 7. Furthermore, there were three scales where patient scores at T2 were statistically significantly worse, with regards to satisfaction: “Doctors’ interpersonal skills” (mean difference of -15 units), “Doctors’ availability” (mean difference of -13 units), and “Comfort and cleanliness” (mean difference of -15 units).

6.3 QUANTITY OF INFORMATION, INFORMATION EXCHANGE AND HEALTH RELATED QUALITY OF LIFE

Aspects of information were presented in **Paper I, III and IV**. Results for as the study-specific questionnaire are presented in the thesis. Primarily, information as perceived by patients was investigated in **Paper IV**, where the patients responded to the EORTC QLQ-INFO25. Patients’ assessed information provision at T0 and at T1. Comparisons regarding the scales’ mean scores were performed between the Comparison wards and the Intervention ward at both points of measurement. At baseline, no differences between the groups could be observed. No improvements were identified regarding any of the scales at T1 for the patients who had been exposed to PCH. There were, however, differences between the groups, maintained also in the adjusted analysis. At T1, patients at the Comparison ward scored significantly higher on the scale “Information about treatments” (mean difference -8 units), and on the satisfaction scale “Satisfaction with the information received” (mean difference -

10 units). Thus, **Paper IV** did not confirm the hypothesis that PCH could be beneficial regarding aspects of information provision as perceived by patients. At the same time, as shown in the second study, patients scored higher on relevant information scales of the EORTC IN-PATSAT32 questionnaire, two years after the first study was carried out and when PCH were established.

The results from the EORTC QLQ-INFO25 questionnaire reflect perceived information provision, quantity of information, and one scale general satisfaction of information. There were no questions regarding the exchange of information between patients and health care providers in any of the validated instruments used in the included studies. While this was the case, one item in the study-specific questionnaire addressed aspects of patients' information provision. The questionnaire is presented in Table 4 where the distribution of responses between the Comparison wards and the Intervention ward at T1 are shown, as well as between the comparison wards at T1 and the same wards at T2, after the introduction of PCH. The item Q2, for example, investigates if the patients' perceived that they had the opportunity to ask questions to clarify given information. At T1, no statistically significant difference ($p=0.361$) was detected between the Comparison wards and the Intervention ward. At T2, a smaller share ($p=0.005$) of the patients exposed to PCH stated they could ask questions in case they did not understand information. Another dimension of information is unwanted disclosure of private information by nurses to other patients or members of staff. The results from Q5 at T2 in the study-specific questionnaire showed a higher proportion of patients who reported that health care professionals had revealed information carelessly, among those who had experienced PCH compared to those who had not ($p=0.009$).

Regarding HRQoL, no differences between the groups on any subscale of the EORTC QLQ-C30 were found at the baseline measures at T0. At T1, patients in the Comparison wards reported a higher degree of nausea and vomiting, as compared to the Intervention ward. This difference was, however, diminished when adjusting for covariables. Consequentially, HRQoL did not seem to be related to PCH.

Table 4. Results from the study-specific questionnaire. Numbers and shares of satisfied patients at the Comparison wards and Intervention ward at T1 and T2 respectively

	T1 Control (n=102) vs T1 Intervention (n=102)				T1 Control (n=102) vs T2 Intervention (n=89)			
	T1C	Satisfied n (%)	T1I	p	T1C	Satisfied n (%)	T2I	p
Q1: Did you get daily information regarding your care during your stay at the ward?	86 (84)	86 (84)	86 (84)	0.858	86 (84)	69 (78)		0.172
Q2: Did you have the opportunity to ask questions if there was something you did not understand in the information given?	97 (95)	95 (93)	95 (93)	0.361	97 (95)	74 (83)		0.005
Q3: Were you encouraged to speak up, in case you noticed something that was wrong or unexpected, during your stay?	67 (66)	72 (71)		0.576	67 (66)	40 (45)		0.001
Q4: Did the staff bring information forward regarding your care and your preferences between the shifts without you having to remind them?	84 (82)	86 (84)		0.578	84 (82)	68 (76)		0.308
Q5: Did the staff reveal sensitive information about your personal circumstances/condition to unauthorized persons (e.g. fellow patients) in your room?	92 (90)	95 (93)		0.421	92 (90)	68 (76)		0.009
Q6: Did the staff respect <i>your wishes</i> when your care was planned, regarding:								
a: Your meals?	79 (77)	83 (81)		0.525	79 (77)	55 (62)		0.009
b: When you wanted peace and quiet?	70 (69)	75 (74)		0.312	70 (69)	49 (55)		0.021
c: When you wanted to take care of your personal hygiene?	81 (79)	83 (81)		0.522	81 (79)	49 (55)		0.001
d: Your discharge from the ward?	86 (84)	89 (87)		0.651	86 (84)	48 (54)		0.001

Q7: Had you wished for more influence on the planning of your care?	86 (84)	77 (75)	0.047	86 (84)	51 (57)	0.001
Q8: Were you aware of what was documented about your care in your medical records?	32 (31)	23 (23)	0.154	32 (31)	30 (34)	0.646
Q9: Did you know the name of the nurse responsible for your care at the ward?	91 (89)	93 (91)	0.432	91 (89)	80 (90)	0.424
Q10: Did you get information on the medications you received during your stay at the ward (pills, injections, infusions, syringes and patches)?	92 (90)	87 (85)	0.134	92 (90)	65 (73)	0.001
Q11: Would you have liked more information on your medications?	13 (13)	17 (17)	0.429	13 (13)	30 (34)	0.001
Q12: Were you encouraged to speak up if you noticed something wrong or unexpected regarding your medications?	54 (53)	48 (47)	0.248	54 (53)	68 (76)	0.001
Q13: Was your risk of falling, tripping or slipping discussed during your stay?	73 (72)	78 (76)	0.418	73 (72)	80 (90)	0.087
Q14: Were there any changes with regard to your medications during your stay at the ward?	56 (55)	62 (61)	0.388	56 (55)	49 (55)	0.965
Q15: Did you fall, trip or slip during your stay at the ward?	5 (5)	10 (10)	0.173	5 (5)	12 (13)	0.035

6.4 ASPECTS OF PATIENT SAFETY

There was no formal evaluation of patient safety in relation to PCH in any of the studies included in the thesis. However, some questions in the study-specific questionnaire addressed this issue, and it was often brought up spontaneously and discussed by nurses during the interviews in **Paper II**.

In the subtheme *Benefits for patient safety*, the nurses considered which aspects of PCH that could affect patient safety. The action considered most important, was to examine the patient and his/her medical condition immediately and in real life, rather than just reading about it in the electronic health record. For example, nurses described how they could assess and examine wound dressing, drainages, and on-going drug infusions and immediately form their priorities in a safer manner. The involvement of patients in discussions about safety related issues during PCH was also brought up as promoting patient safety. This could for example concern fall risk and fall preventive measures, or medication issues. One item (Q13) in the study-specific questionnaire concerns if the patients had talked about their risk of falling with the nursing staff during their stay. Consequently, a large share (ranging from 72 % to 90 %) of the patients reported having done so. Even though the largest share (90 % among patients at T2) was found at an Intervention ward, there were no statistically significant differences on this matter between patients who had experience of PCH and those who had not.

In item Q3 in the same questionnaire, patients reported to which degree they were encouraged to speak up on patient safety issues. In contrast to the idea that PCH would facilitate for patients to speak up, a larger share of the patients (66% compared to 45%, $p=0.001$) who had not experienced PCH stated they had been asked to speak up. However, a result to the contrary was found in Q12 at T2, where a larger share of patients exposed to PCH reported they had been encouraged to speak up with questions or deviations regarding their medications (76 % compared to 53 % among those not exposed, $p=0.001$).

6.5 INDIVIDUALIZED CARE

The degree to which the patients' perceived the nursing care as individualized was investigated in the second study, using the ICS among 90 patients. There were no previous data on individualized care within the PCH project. Thus, the results from the questionnaire shown in Table 5 comprise of mean scores of the different scales and their confidence intervals from a single measurement. The scale "Personal life situation" received the lowest scores in both ICS-A and ICS-B. The items included in the scale concern if nurses take the patient's life outside of the hospital into account when shaping their care (ICS-A), and whether those nursing activities actually affected the care (ICS-B). Higher scores were found

on the “Decisional control” scales, reflecting if nurses invited patients to participate in decisions regarding their care (ICS-A) and whether patients’ decisions did influence their care (ICS-B).

Table 5. Response rates, mean scores, and confidence intervals of the ICS-A and ICS-B and their subscales among patients participating in Paper III (measured solely at T2).

	n(%)	Mean* (95 % CI)
Support of individuality (ICS-A)	84(93)	3.46 (3.19-3.73)
Clinical situation	84(93)	3.71 (3.46-3.96)
Personal life situation	83(92)	3.03 (2.74-3.32)
Decisional control	83(92)	3.47 (3.21-3.73)
Perceptions of individuality (ICS-B)	81(90)	3.69 (3.42-3.96)
Clinical situation	81(90)	3.85 (3.6-4.1)
Personal life situation	75(83)	3.07 (2.77-3.37)
Decisional control	81(90)	3.91 (3.66-4.16)

*Range 1-5

6.6 NURSES’ PERCEPTIONS OF PERSON-CENTERED HANDOVERS

The interviews and their analysis resulted in three main themes and ten pertinent subthemes (shown in Table 6), further presented in **Paper II**. The main theme *Clinical communication and assessment* refers to information on how nurses interacted and communicated with patients, visitors and co-workers at the wards in relation to PCH. The subtheme *Consequences for the nurses’ daily workflow* included nurses’ concerns regarding the logistic challenges of PCH. For example, some participants described PCH as being time-consuming, especially for patients who were expected to be talkative or “complicated”. Another challenge was to coordinate the handovers with colleagues, to meet up with the right person at the right time. In contrast, PCH were described as more efficient than standard handovers. The perceived efficiency was often related to PCH being more informative and facilitated a quicker start of the shift. The subthemes *An opportunity for learning* and *Impact on teamwork* were partly intertwined, as the nurses described their often complex approach towards assistant nurses during PCH. PCH could function as an opportunity to teach and instruct assistant nurses about medical and nursing tasks at hand, but at the same time, nurses described frustration regarding the perceived passivity among assistant nurses, and unwillingness to learn. On one hand, PCH were opportunities both for teaching, mutual understanding and improved teamwork for the rest of the shift, but could, on the other hand,

create frustration and expose a sometimes complicated relationship between registered nurses and assistant nurses.

Several nurses who were interviewed also reflected upon information provision and information exchange. In the subtheme *Possibility for information exchange*, the participants conveyed perceptions of PCH as times for them to provide information to patients in a structured manner. Some nurses described how they used preset terms from the electronic health records to inform patients about e.g. nausea, stomach issues, pain, psychosocial issues etc. The perception that information foremost concerns transfer of information from nurse to patient was dominating. Some nurses, however, nuanced that idea and highlighted the importance for them to collect information from the patients instead. This was considered particularly relevant when planning the shift together with the patient, and when nurses needed a better understanding of the patient's status.

The subtheme *Involving patients in the handover* also revealed incongruous perceptions of patient participation in relation to PCH. Several nurses described how PCH could be the single opportunity during their shift that was reserved for talking to patients, and for the patients to be encouraged to influence their own care. For patients and nurses being able to communicate unconditionally was often described as an ideal. There were, however, significant barriers for participation. Among several, the physical environment surrounding PCH was highlighted. Most often, the patient stayed in their bed while the nursing staff stood around the bed, looking down. This was described as uncomfortable and reinforcing the hierarchical structured preventing patients from participation. Some nurses reported that their colleagues preferred to talk to each other, rather than to involve the patient, and that they tended to focus on medical tasks at hand rather than finding out what mattered most to the patient.

Outside of the themes presented in the manuscript of **Paper II**, the participating nurses provided additional information regarding suggestions for improvements and future perspectives for PCH. This data did not correspond to the study's primary aim, but were still considered to be of interest. A recurring notion was that more education, and repeated education, on the purpose with and content of PCH would improve its delivery. For example, they asked for education days away from the ward where they could engage in role-play and watch instructional films. Discussions about PCH among the nurses were also requested. Several nurses were worried that patient participation was hampered because the patients had not received adequate information about PCH in advance. Thus, they suggested improved information, both written and oral, to patients at for example admission or during the mornings.

Table 6. Summary of all main- and subthemes extracted from the interviews in Paper II.

Main themes	Subthemes
Clinical communication and assessment	<p>Consequences for the nurses' daily workflow</p> <p>An opportunity for learning</p> <p>Supporting nursing care and challenging the nurse role</p> <p>Impact on teamwork</p>
Opportunity for patient participation	<p>Involving patients in the handover</p> <p>Possibility for information exchange</p> <p>Patients' apprehensions of PCH as interpreted by nurses</p>
Consequences for nursing care	<p>Benefits for patient safety</p> <p>Integrity concerns</p> <p>Significance of patients' visitors during PCH</p>

7 DISCUSSION

The studies included in the thesis represent different ways of evaluating PCH and describe its consequences using various outcomes. The findings will be discussed per outcome, while the methodological discussion deals with the quantitative studies and the qualitative study respectively.

7.1 DISCUSSION OF FINDINGS

7.1.1 Patient satisfaction

The primary endpoint of the PCH project was patient satisfaction, assessed at a total of three points of measurement in two studies. These comparisons showed mixed results, but indicated higher satisfaction regarding exchange of information between caregivers and nurses' information provision, among patients who took part in PCH. In the first study, patients at the Intervention ward scored "Exchange of information between caregivers" higher than patients at the Comparison wards. This difference was statistically significant, but at the time we still interpreted the overall result as negative since no improvements were observed on any of the other subscales of IN-PATSAT32. Instead, the scores were consistent, both between the wards at baseline, and between baseline and T1. In addition, the scores were much similar to those presented in the large validation study by Bredart *et al* (98). The second study confirmed the results from the first study regarding the positive consequences of PCH on patients' satisfaction with exchange of information between caregivers, as well as showing a statistically significant improvement on satisfaction with nurses' information provision, after the introduction of PCH. Surprisingly, the patients the second study also reported significantly lower satisfaction with dimensions regarding physicians and comfort and cleanliness at the wards, but these aspects could hardly be influenced by PCH. Together, both studies present support for PCH as means to increase patients' satisfaction regarding information exchange between nurses and information provision from nurses.

Patient satisfaction is, as has been described above, a multi-dimensional outcome. It covers numerous aspects of the patient experience and is used to quantify patient-relevant perspectives of hospital care (45). We did not expect all dimensions to be affected by PCH, but primarily those related to information provision, information exchange, nurses' availability, and perhaps overall satisfaction. None of the previous studies that used patient satisfaction as an outcome measure of shift handover interventions involving patients have used the EORTC IN-PATSAT32, preventing direct comparisons of levels of satisfaction. It is, however, possible to relate our results to similar dimensions of satisfaction shown in other studies. For example, Sand-Jecklin *et al* (48) showed improvements in the item "Pass along important information from shift to shift" postimplementation of bedside handovers, highly resembling "Exchange of information between caregivers". Cairns *et al* (51) saw higher

agreement among patients to the statement that nurses kept them informed, after implementing bedside handovers, which is similar to satisfaction on “Nurses’ information provision”. A recent study by Schirm *et al* assessed patients’ satisfaction with nursing care specifically, before and after implementing bedside handovers (130). They included five items, regarding if patients perceived that they were treated with respect, if nurses listened, if nurses explained things well, if they could discuss worries with nurses, and if they trusted the nurses. Such questions, of a more relational character, differ from those commonly investigated in relation to handover interventions, and the authors could not report any statistically significant improvements post implementation. It is notable how many previous studies have chosen to measure patient satisfaction with either study-specific questionnaires, or have picked items from existing instruments to fit with the handover intervention. The patients who participated in the PCH project were asked to evaluate their hospital stay as a whole, not only the nurse handovers. PCH constitute but a small part of the patient’s day at an inpatient ward which can be full of interactions with staff and information from different professionals. Thus, an intervention based on information exchange must be powerful to be reflected in a general satisfaction score since it competes with all other interactions and patient experiences during the admission. These circumstances may have influenced the possibility to detect an effect of the intervention.

Patients’ satisfaction with “Exchange of information between caregivers” was the leading endpoint of the PCH project and the sample size calculations were based on that scale’s scores. In both studies, results favored PCH with regard to this outcome. Exchange of information between caregivers could be interpreted in many ways. It is possible that the higher satisfaction among patients who experienced PCH reflects their presence during the handover and that they actually got a chance to evaluate the nurse-to-nurse communication, in contrast the controls. At the Comparison wards, they were not invited to participate in the handovers at all, making them more difficult to assess. In an interview study with patients who experienced bedside handovers, McMurray *et al* (59) describe how some patients preferred to be passively engaged in the handovers, and listen to the nurses’ information exchange, rather than being actively involved themselves. Also, Radtke (131) showed improvements in a survey on nurse communication as perceived by patients after implementation of bedside handovers. These outcomes are somewhat problematic since they do not tell us about the patient’s role in the information exchange.

There were larger effect sizes in satisfaction scores favoring PCH the second study than in the first study. The second study was carried out approximately two years after the first, and the implementation process should have matured at that time. The evaluations in the first study commenced about one month after the initial introduction of PCH at the intervention ward. It is possible that time and the ongoing implementation improved the consistency and delivery of PCH among nurses, and that this is reflected in patients’ ratings of care. McMurray *et al*

(28) describe the introduction of bedside handovers as dramatic for nurses, as it is considered a major challenge to change daily routines, especially when changes relate to communication. It has also been described that implementation processes in clinical practice can be lengthy, and that sufficient time should pass before full effects of the intervention can be expected (95, 132-134).

The patients who participated in the studies all had a cancer diagnosis and had recently been admitted to oncological inpatient wards, consequentially they were in a relatively poor physical condition and in a vulnerable phase of their cancer trajectory. Increased disease burden and toxicity from cancer-specific drugs have been described as determinants of patient satisfaction among patients with cancer (102). Also, having cancer has in itself been shown to be the most important factor for patients when assessing quality of care outcomes such as patient satisfaction (135). In the multivariable analyses performed in our studies, included in the thesis, educational level, age, sex, and treatment intention were controlled for as these factors were hypothesized to possibly explain some of the variation in satisfaction scores.

7.1.2 Information provision and health related quality of life

HRQoL and information provision as perceived by patients, were investigated in the first study (**Paper IV**). The results indicated that PCH were not related to these outcomes. The patients' ratings were overall consistent, independent of exposure to PCH.

During the design phase of the study, there was no specific hypothesis regarding HRQoL. It was deemed unlikely that an intervention such as PCH could influence such outcomes, taking the patients' health status and context into account (136, 137). To our knowledge, there have been no previous studies investigating changes in symptom burden or physical functioning as outcomes of a nurse handover model. However, there are associations between quality of information and communication and aspects of HRQoL. For example, among cancer survivors, prostate cancer patients, and young adults with cancer, unmet information needs have shown to be positively associated with lower HRQoL (138-141). Possibly, these associations are not evidence of a causal effect of quality of information and communication on aspects of HRQoL. Instead, persons suffering from low HRQoL are likely to be more dissatisfied with health care overall (142). In their review of eight interventions intended to improve information provision among cancer survivors, Husson *et al* (143) found only one that showed positive effects on HRQoL as well. Knowing this, there were still reasons to include HRQoL in the evaluations of PCH. The instrument EORTC QLQ-INFO25 was chosen to evaluate information provision. This questionnaire is a module to the HRQoL instrument EORTC QLQ-C30. The information-module was developed and validated

together with the HRQoL instrument and they are intended to be administered together (105, 144). Out of transparency, possible interest to readers, and responsibility to the patients who took their time and filled out the questionnaires, the results from the HRQoL surveys were presented in **Paper IV**. Also, the patients' ratings of their HRQoL provide valuable information on their health status. As compared to the general Swedish population, the patients participating in these studies scored, as expected, higher on the symptom scales and lower on the functional scales (111).

Regarding information provision, several previous studies assessed the possible impact from bedside handovers. In a literature review from 2014, Gregory *et al* (136) mapped all types of positive effects that were published regarding bedside handovers on patient and nurse outcomes. Despite many attempts to improve patients' satisfaction with information provision, no quantitative study had managed to do so. This does not seem to have changed since 2014. However, **Paper III** in this thesis shows positive results regarding patients' satisfaction with "Nurses' information provision" and PCH. This finding stands out among the other studies evaluating models of bedside handovers and could perhaps reflect the longer-term perspective of evaluation. Instead of breaking through in quantitative analyses where questionnaires are employed, aspects of information were often raised in qualitative studies where patients were interviewed on their experiences of participating in nurse handovers (58, 59, 65). It is possible that bedside shift reporting models are simply not powerful enough interventions to stand out in competition with all other information-rich activities that form a patient's hospital admission to show in quantitative evaluations. It could also be that the handovers were not performed in a way that met the patients' expectations and needs regarding information.

7.1.3 Individualized care

The results on patients' perceptions of individualized care were presented in **Paper III**, and were gathered from one point of measurement. Thus, no comparisons were possible. The association between individualized care and PCH could therefore not be investigated. The patients' in our study scored lowest on the scales "Personal life situation" in both the ICS-A and the ICS-B. This corresponds well with results from previous surveys among cancer patients (115, 145). The items in "Personal life situation" deal with personal information, such as hobbies, previous hospital experiences and family relationships. Ceylan and Eser (146) discuss that the consistently lower scores on these scales could either depend on nurses' negligence of patients' personal lives, or that patients' medical needs are prioritized in financially strained health care organizations. Also, the results from the ICS do not convey whether patients actually wish for these dimensions of their personal life to be accounted for when admitted to a hospital ward. During PCH, it is likely that both patients and nurses focus on the practical issues at hand, rather than the patients' personal life outside of the hospital.

When scrutinizing the items in ICS-A and ICS-B, the scales “Decisional control” seem to best match the components of PCH. Shared-decision making has been presented as one factor influencing perceptions of individualized care, as well as educational level, and length of stay (147). Of these factors, nurses can primarily impact shared decision making. PCH aims at enabling patients and nurses to plan for the upcoming shift in collaboration. Hence, it is theoretically possible that PCH can facilitate individualization in decisional control of care as patients get a daily opportunity to express their wishes and influence the delivery of health care.

Overall, the patients in the second study rated *how* nursing care supported individuality (ICS-A) lower than how individualized the care was actually perceived (ICS-B). This is also congruent with findings from other studies with various patient groups (148-150).

Interestingly, this pattern cannot be found when nurses assess individuality of care with the ICS-nurse questionnaire (151-153). Apparently, there is a discrepancy between patients’ and nurses’ assessment of care and health care practice. It seems logical that nurses would be more aware of nursing interventions from an overall perspective, while patients get glimpses, and are often not part of the task planning that nurses perform. Also, nurses might overrate the impact of certain interventions on the patients’ overall experience, while the patients take more factors into account (146). Although not shown in the results from the second study, PCH could possibly enhance patients’ awareness of nurses’ interventions to promote individuality of care. For example, we interpreted the improved ratings of patients’ satisfaction with exchange of information as a consequence of patients actually seeing and hearing the handovers that used to be performed in a secluded area. If performed thoughtfully, PCH could be an opportunity to further invite patients into partaking in planning and carrying out nursing interventions to a greater extent.

7.1.4 Nurses’ perspectives

In **Paper II**, the nurses’ perceptions of PCH were described. In the interviews, the nurses shared their experiences of working with PCH, and their perceptions generated three main themes in the final analysis: “Clinical communication and assessment”, “Opportunity for patient participation”, and “Consequences for nursing care”. The participating nurses described many advantages with PCH, especially when contrasting to their previous model of handover. At the same time, they conveyed insecurities regarding bedside communication and barriers for patient participation.

A recurring notion was that nurses perceived it as difficult to involve patients to a sufficient degree in the handovers. In their interview study, Bruton *et al* (100) describe that both patients and nurses reported the view that bedside handovers were primarily an opportunity

for nurses to exchange information while the patient could listen. This type of handover was not desired when implementing PCH, and much focus during the implementation was put on emphasizing the patient-nurse communication and exchange. As mentioned, bedside handovers could even worsen patients' sense of participation if performed between nurses only and when technical language and medical jargon is used (26). Despite the good intentions, the participants in reported how some of their colleagues lapsed into practices resembling nurse-nurse handovers during PCH. Nurses in other studies evaluating bedside handovers have reported discomfort with allowing the patients to participate (56, 154). It is possible that this factor was underrated during the implementation phase of PCH, and not recognized enough during the educational sessions and discussion with nurses. Still, all nurses described PCH as an opportunity for increased participation and some used wordings such as "patients can be persons in this situation". Perhaps this is reflecting a shift of attitudes, or that PCH could facilitate building better relationships between nurses and patients.

Information and information exchange were often brought up by the nurses as core concepts of PCH. There were most varying perceptions as to what sort of information exchange would be optimal during PCH. Some nurses were certain that information transfer from them to the patients were most important, while others put a higher value to the information they received from patients. In the person-centered care context, it has been described that too much information can lead to passivity among patients, hindering their engagement in communication (155). Patients can gain a sense of security, that nurses will take care of everything and their role is to be informed of the results. Possibly, PCH could have this consequence if nurses perceive patients as passive recipients of information, rather than expecting a mutual exchange (156).

Several nurses perceived that patients were not sufficiently prepared for PCH. The patients were thought to be inadequately informed about the procedure, what was expected of them, and that they could use PCH as an opportunity to influence their care. Some nurses blamed this on the nurse assistants not doing their job properly, as they perceived it was their designated task to prepare patients for PCH. The daily preparation phase of bedside handovers has been described as vital for successful implementation (157, 158), foremost because patients can prepare questions. Giving the patients a chance to prepare, just as the nurses do, might also even out the hierarchies in the handover situation. In their suggestions for improvement of PCH, several nurses highlighted strategies to enhance patients' awareness of PCH, for example informing patients at admission.

When discussing the context with regard to nurses' role in PCH, adherence to the PCH protocol (presented in Table 1 in the Background section of the thesis) is a vital aspect as it determines the actual delivery of the intervention evaluated in the thesis. It has already been

mentioned that evaluations might have started too soon in relation to the implementation process in the first study. The nurses in the interview study were unanimously wishing for more training and education, especially for their colleagues. Out of the 11 participants, 6 had worked at the wards for a year or less (but no less than 6 months), consequentially, they had not partaken in the initial educational program during the implementation phase. Instead, they were taught by their senior colleagues. In their large observational study examining nurse adherence to a bedside handover protocol, Malfait *et al* (159) conclude that a shorter educational program (2-6 hours) constitutes sufficient training for nurses prior to implementing bedside handovers. Slade *et al* (160) specifically evaluated a training program for bedside handovers among 26 nurses, where 13 participated and 13 did not. The trained nurses showed a far better adherence to protocol during handovers, and managed to interact more respectfully and multifaceted with patients. They were also better informed regarding the patients' status and plans. For the PCH project, no additional formal training for nurses was offered apart from the educational sessions preceding the start of PCH. It is possible that this affected the output of PCH, especially in times of high nurse turnover.

7.2 METHODOLOGICAL CONSIDERATIONS

In the following section, the strengths and limitations of the methods chosen for the studies in the thesis will be discussed.

7.2.1 Quantitative data

7.2.1.1 Design

The study designs chosen for the two studies evaluating patients' perception were cross-sectional with independent groups. In the first study, a parallel group design was employed where measurements occurred simultaneously at the Intervention ward and the Comparison wards at both baseline and T1. The second study employed a pre-post implementation design with independent groups, where the wards served as their own control. No longitudinal data were collected on an individual level as a consequence of the fact that most patients only stayed at the ward for a short period of time. Thus, patients could only respond once. This hampered the possibilities to infer changes over time among individual patients, after they were exposed to PCH. On the other hand, such a design would not have been feasible in the acute inpatient setting where there are no certainties regarding readmission to the wards. Instead, the initial idea was to regard the wards as the units of analysis and employ a quasi-experimental design, more precisely a nonequivalent control group before-after design (96). In a quasi-experiment, no randomization occurs, and the researchers control the assignment of participants to either exposure or non-exposure (161). The primary drawback of this design is that it is impossible to eliminate bias from confounding, obstructing causal inference. Another issue in our specific setting was the independent groups and the lack of longitudinal

data. In quasi-experiments, individuals are followed over time, and as mentioned, this would not be possible in our setting. Thus, the studies cannot be regarded as quasi-experimental, but rather cross-sectional with independent group comparisons, but with baseline measurements. In the first study, there was a parallel control group, eliminating the confounding factor of time.

A causal relationship between PCH and the observed outcomes could have been established if randomization had been possible. Because of the nature of the PCH intervention, randomizing patients to different types of handovers within the wards were considered impossible. Nurses at a ward cannot be expected to employ different handover styles for different patients. This would also introduce a risk of a spill-over effect from PCH to the standard handovers, contaminating the controls. Neither would it be ethically defensible to randomize patients to wards depending on the ward's handover style. The wards in our studies had different tumor-specific specializations, which determined the patients' admissions. A final option, often used when investigating complex interventions, was cluster-randomization where, in this case, the wards would be randomized to serve as intervention or control (94). The successful implementation of an intervention such as PCH was, however, highly dependent of local factors, such as the staff's willingness to participate, encouragement from management, and devoted individual nurses (92). In our case, implementing bedside handovers was already planned for at the Intervention ward, before the study was designed. It was therefore not considered feasible to randomly allocate the three wards to either group. Interest in PCH was also expressed in the Comparison wards, but the implementation was postponed at those wards. For future studies on PCH, involving more than one ward or hospital, cluster-randomization should be considered early in the planning stage. To partly compensate for the lack of randomization, co-variables known to possibly affect the dependent variables were included in the regression analyses. These analyses could, however, only be performed for known confounders, and it is possible that unknown confounders have affected the results, threatening the internal validity.

7.2.1.2 Type I and Type II errors

Hypotheses were tested in both studies of patients' perceptions. When performing such tests, there is always a risk that observed results are due to chance, rather than a true difference between the studied groups. The differences found between the Intervention group and the Comparison groups might reflect chance, or a factual difference. There are two types of random errors in hypothesis testing. Type I means that a false positive difference is observed. Type II errors means a true difference is missed. To determine the risk of drawing inaccurate inferences in form of a Type I error from the data, a level of significance is set. In our studies, the level of significance was set to 5 %, which gives a probability that a true null hypothesis would be rejected 5 times out of 100. A lower level of significance would decrease the risk of

performing a Type I error, but at the same time increase the risk of performing a Type II error e.g. missing true differences. In our studies, multiple testing was performed where tests of statistical significance were employed numerously. In summary, there is a low probability that we have made a Type II error, and a higher risk that the observations reflect chance (162).

7.2.1.3 *Internal validity*

Internal validity of a study refers to the degree to which the observed effects were caused by the intervention (in this case, PCH), rather than extraneous factors that were not controlled for. The issue of non-randomization was discussed above, but there were other threats to internal validity in the studies.

Firstly, whether the observed results mirror the introduction of PCH at the wards is highly dependent on if and how PCH were carried out in reality. A lot of emphasis was put into the implementation phase of PCH (described in the Background section of the thesis) to increase the adherence to the PCH protocol and consistency of its delivery among the nurses (19). The follow-up regarding delivery of PCH was informal and relying on reports by nurses and nurse managers at project meetings. Observations of the handovers were performed by two nurses writing their master's thesis within the PCH project. Otherwise no active monitoring took place. Instead, nurses were encouraged to speak up and raise concerns and questions should they encounter difficulties in carrying out PCH. This might have been a naïve strategy, especially when considering the problems in delivery described by nurses in the qualitative study. In addition, other studies where bedside nurse handovers were observed reported deficits in adherence, especially regarding the patient safety and patient participation components (60, 159). The first evaluation started swiftly after the introduction of PCH at the Intervention ward. At this time, the intervention may not have gained full effect, which could have diluted the results. We did not investigate potential differences in outcomes between the beginning and the end of the intervention period, which could have further elucidated the implementation process.

Experimental research is characterized by *manipulation* (the researchers intervene, e.g. implementing PCH), and *control* (having control over the experiment and control group) (96). In our design, it was crucial for internal validity to maintain standard handovers in the Comparison wards to avoid contamination of the results. There were no formal observations or monitoring of the Comparison wards during the study period. However, one of the Comparison wards employed “patient-centered rounds” during the study period, where patients who wanted were invited to join the nurses and physicians in the medical rounds. This practice bears similarities with PCH and could have affected the studied outcomes.

Another threat to the internal validity concerns selection bias. Selection bias is a systematic error concerning the sampling procedures of a study. In all studies, there is a risk of selection bias, primarily because of data collection procedures and non-participation. This could mean that the patients who chose to respond were not representative of the population, or that the nurses screening for inclusion in the first study selected patients. The overall response rates varied substantially between the studies and between 25 % and 39 % of patients asked to participate did not respond. This relatively low response rate is probably due to the fact that the patients were severely ill, and might have introduced a bias in the results. The difference between the studies in response rate could be explained by the different strategies regarding data collection that were used. In the first study, ward nurses managed the inclusion of patients, while I informed patients in the second study and asked them about participation. It is probable that neither patients nor nurses at the wards had the research project as their main focus during patients' discharge, and the study information was given together with all other oral and written information that patients receive upon discharge from the wards. In the second study, I approached the patients at any time after they had stayed for at least three days, and many chose to respond to the questionnaires during their stay at the ward. This procedure could have reduced the risk of questionnaires being forgotten, but at the same time might have increased the risk of social desirability. Furthermore, we deliberately chose not to gather background variables for patients who were asked to participate but chose not to return their questionnaires in any of the studies. Had we done so, tests between responders and non-responders could reveal systematic sampling bias within the study population (96). However, the patients' integrity was valued higher, and non-respondents had not given their consent for us to get access to their electronic health records.

Narrow inclusion criteria could also cause a sampling bias by excluding a large share of patients, who are intended to receive the intervention in a real-world setting (60). When designing the studies, this was considered with certain caution since PCH is an intervention intended for all patients treated at a ward. Due to financial and pragmatic reasons, patients had to understand Swedish to be able to participate in the evaluations of PCH. Apart from this, the inclusion criteria were wide and intended to include most patients who were admitted to the wards.

7.2.1.4 External validity

External validity concerns the generalizability of a study, and to which degree the findings are valid for other samples or settings than the ones studied (96). The PCH studies were conducted in an oncological inpatient setting, only involving patients with cancer. The PCH intervention itself, however, does not include cancer-specific components and is considered to be applicable in most adult inpatient settings. The questionnaires chosen for the evaluation of PCH were all, apart from the ICS, developed for cancer patients which might affect the

generalizability of the results to other patient groups. On the other hand, patient satisfaction and information provision are not outcomes valid only for patients with cancer. All studies in the thesis were performed in a real world-setting, and PCH were implemented and evaluated at regular acute oncology wards. This caused problems regarding control of the intervention's delivery, and of confounders, but was an advantage for the studies' external validity. An artificial setting would have provided more ideal circumstances for research, but the results would not have been valid for a true hospital setting (96).

7.2.1.5 Choices of instruments

The outcomes in the first two studies were investigated with patient questionnaires described in detail in the "Methods" section of the thesis. A major strength of the studies was the use of validated instruments from the EORTC, increasing the probability of actually measuring what was intended. This was not the case for the study-specific questionnaire, and consequentially, the results for this questionnaire should be interpreted with caution. The EORTC IN-PATSAT32 was developed and tested for oncological inpatients. It has also been shown to mainly measure satisfaction with nurses (163), fitting the PCH intervention. The EORTC QLQ-INFO25 was chosen early on in the design phase to measure information provision as perceived by patients. By that time, the awareness of information exchange and the consideration of patients' information provision to members of staff was not as widespread as in more recent years. The EORTC recently developed an instrument, EORTC QLQ-COMU26, intended to assess communication between patients with cancer, and professionals (164). Dimensions of the instrument include patients' assessments of mutual respect, sufficient time for information exchange, acknowledgement of the patient's feelings, and understanding of the patient's perceptions of the situation by the health care professionals. Had we designed the studies again, it is likely that an instrument like EORTC QLQ-COMU26 would have been used instead, better capturing components of PCH.

The ICS was added later in the project and first introduced in the second study. This prevented any statistical inference and conclusions to be made regarding the possible effects of PCH on the perceptions of individualized care. As described above, the ICS-nurse version was first intended to be administered among the nurses. This would have provided a broader understanding of the results from the ICS-patient (152). The ICS could potentially be a feasible and relevant instrument for future evaluations of PCH or similar interventions.

7.2.2 Qualitative data

When discussing the quality and rigor of scientific inquiries using a qualitative method, the term trustworthiness is often used as an alternative to validity (96, 165). Qualitative inquiries

respond to other questions than quantitative ones. For example, “What characterizes this phenomenon?” instead of “how much or how many?”. A qualitative study usually seeks to describe meaning and implications of phenomena, rather than mere categorization (166). Because of the different nature of both the data collected in the study of nurses’ perceptions and the methods used for analysis, a separate methodological discussion will follow. Lincoln and Guba (167) suggested a framework with criteria for assessing and discussing trustworthiness in qualitative studies. These criteria are: credibility, dependability, confirmability and transferability.

7.2.2.1 Credibility

Establishing credibility is often referred to as the overarching goal in qualitative research. It deals with the confidence in truth of the data and its interpretations (168). Data were generated through interviews and thus the credibility of the study was highly dependent on how these interviews were performed. The research team that had worked with PCH for several years, and AK, MB, YB and LS all had established connections with the nurses that were to be asked for participation in the study. The team also had preconceptions regarding PCH and its implementation at the wards. In order to avoid bias related to this in the interview situation, an experienced researcher (OD) with no previous ties to the PCH project was involved in to carry out the interviews. Also, involving a senior interviewer with previous experience from performing interviews in research settings could enhance the richness of the data (165). Using an interview guide, could introduce bias as the questions might lead participants into reasoning that does not reflect their true perceptions. At the same time, approaching the nurses without any topic guide could have had yielded a material not corresponding to the aim of the study. The interview guide was not pilot tested, but based on previous research, and input from all researchers involved in the study. It is possible that aspects of the nurses’ experiences of PCH were not covered in the interviews because of the preset questions. On the other hand, the interviewer was free to adapt the guide depending on each dialogue, and all interviews included open questions allowing the participants to express themselves freely.

Credibility can also be affected by the sampling strategies used. The aim of the study was to achieve a full population sample, where all nurses who fulfilled the inclusion criteria were asked to participate. Nurse assistants were not asked to participate in the study, despite their presence and participation in PCH. The decision to interview registered nurses only was taken because they represented the primary performers of PCH. Nurse assistants, on the other hand, were only partaking in PCH when they were not otherwise busy. It is possible that the findings of the study would have been more comprehensive if the perspectives of nurse assistants had been investigated as well, especially regarding teamwork related to PCH. Thus, this decision might form a threat to the credibility of the study regarding its truthful

representation of the real-world setting where PCH are performed. However, almost all (11 of 13) eligible registered nurses chose to participate, which promoted variability and reduced the risk of sampling bias.

Credibility also deals with how well the themes cover the data (126). The aim of the interview study guided the analytic process and the identification of meaning units. Consequentially, some data were not considered relevant to be taken further in the analysis. The researchers who performed the analysis were aware of the possible bias regarding preconceptions about PCH. Also, the analyst triangulation decreased the risk of missing relevant information conveyed in the interviews. Information regarding nurses' suggestions for the development of PCH was presented as supplementary material, since it did not match the aim of the study but was still considered to be of interest.

7.2.2.2 Dependability

For qualitative studies, dependability can be regarded as the equivalent term to reliability in quantitative contexts. If data are dependable, they are stable over time and contexts. The nurses were interviewed only once, but the data collection period lasted over six months. There were no obvious differences regarding the data in the first interviews compared to the last. Also, all interviews were performed by the same person, which would enhance dependability. Even so, the interviewer adapted each interview to the participant depending on the flow of the dialogue, meaning that no interview was exactly like the others. Regarding interpretation of data, analyst triangulation and discussions in the research group were performed to increase the dependability (165).

7.2.2.3 Confirmability

The confirmability of qualitative data refers to the accuracy of interpretations and how well the final results mirror the participants' voices rather than the researchers' perspectives. To enhance confirmability, analyst triangulation (165) was applied, in which several researchers (AK, MB, and YB) carefully read the interviews and performed the thematization partly independently. This reduced the risk of interpretations being biased by a single researcher's preunderstandings. The three researchers were however working in the same research group and might have had similar preconceptions about PCH. Due to practical restraints, no member checks were performed, i.e. the nurses themselves were not invited to review the interpretations during the analytic process. This could have strengthened confirmability (167). When performing the analyses, the intention was to promote a text-close representation of the material, involving careful interpretation. When presenting the analytic flow, we attached a flowchart and described an audit trail, to further enhance confirmability. The

readers are hopefully able to clearly follow the transit from original data to subtheme/main theme (168).

7.2.2.4 Transferability

Transferability is the qualitative counterpart of the quantitative term generalizability and refers to the extent to which the results can be transferred to other persons and settings than the ones studied. The sample was small (11 participants), and drawn from a single setting (two acute oncological inpatient wards at one hospital). These aspects could hamper transferability to other nurses in other settings. There was, however, a thorough description of the context relevant for the participants, primarily the environment at wards, but also of PCH. A thicker description of contextual factors facilitates other researchers' or clinicians' consideration of the findings in their specific settings. Also, PCH is a practice-oriented intervention, not principally dependent on the patients' diagnoses. Therefore, the nurses' perceptions of PCH could be relevant also for other inpatient settings.

8 CLINICAL IMPLICATIONS AND GENERAL CONCLUSIONS

The results presented in this thesis add to the body of evidence regarding models of bedside handovers. The studies are, to our knowledge, the first to evaluate a model like PCH in the oncology setting, and to employ a design with parallel control groups. The first evaluation (**Paper I** and **Paper IV**) showed no improvements favoring PCH regarding patient satisfaction, information provision as perceived by patients, or HRQoL among the responding patients. By the second measurement (**Paper III**), patients' satisfaction with exchange of information between caregivers and nurses' information provision, was higher among those who were discharged from wards where PCH had been implemented, compared to those who were not. The results indicate that the process of introducing PCH and implementing it fully takes time, and it is possible that the full effects of PCH manifest after years of continuous implementation.

The interviews with nurses at the oncology wards revealed that PCH were perceived as feasible and appreciated, and regarded as standard practice after two years. There were, however, discrepancies between the intentions of PCH and the actual delivery, as described by nurses. Evidently, nurses tended to focus on information provision rather than information exchange, and struggled in promoting patient participation during PCH (**Paper II**). Further emphasis throughout the implementation phase of PCH could have been put on the ethical dimensions of person-centered care. Also, discussions with nurses on patient participation and information exchange should be included in any implementation of PCH. Overall, much focus should be put on the implementation process, and to employ a strategy based on theory. Patients should be involved in the development phase to better capture their preferred components in the handovers. It is vital to find out how to best inform patients and their visitors about the handovers during their stay at the wards.

Despite lack of evidence on many dimensions, further development of PCH can be recommended for practice in the oncological inpatient setting. Future evaluations should include cluster randomization, measures on patient safety, patient participation, and perceptions of individualized care.

- PCH have beneficial consequences on patients' satisfaction with the exchange of information between nurses, and nurses' information provision, as compared to standard handovers performed secluded from patients.
- PCH do not affect patients' perceptions of quantity of information.
- PCH do not seem to be linked to patients' HRQoL.
- Aspects of patient safety in relation to information exchange between patients and nurses could potentially improve with PCH.

- Nurses reported advantages with PCH compared to standard handovers.
- Future attempts to implement PCH or similar models of bedside handovers should have a long-term strategy for continued education and training for nursing staff.

9 POPULÄRVETENSKAPLIG SAMMANFATTNING

9.1 BAKGRUND

Varje år vårdas cirka 70 000 personer inlaggande på sjukhus på grund av cancersjukdom. Att vårdas på en slutenvårdsavdelning kan upplevas påfrestande för patienter och närstående. Det råder ofta osäkerhet kring prognos och vad som kommer att ske, samtidigt som den normala livsföringen sällan kan upprätthållas på en slutenvårdsavdelning. Många patienter som vårdats inlaggande har rapporterat att de fått otillräcklig information och att de inte i tillräckligt hög grad upplevt sig delaktiga i beslut som rör deras vård och behandling. Flera initiativ har tagits under de senaste åren för att förbättra patienters nöjdhet avseende information och delaktighet. Sjuksköterskors rapportering mellan arbetspassen har identifierats som en aktivitet som skulle kunna främja ett bättre informationsutbyte mellan patienter och vårdpersonal, och därvid förbättra patienters möjlighet att delta i planeringen av sin vård tillsammans med vårdpersonalen. Traditionellt så har sjuksköterskor genomfört rapporteringen mellan arbetspassen avskilt från patienterna, oftast utan given struktur. Mot denna bakgrund har flera forskare infört och utvärderat modeller av rapporter mellan arbetspassen som involverar patienterna på olika sätt. Det finns vissa, men otillräckliga, belegg för fördelar för patienterna att få möjlighet att medverka som aktiva deltagare i överrapporteringen.

Personcentrerad rapportering mellan arbetspassen implementerades med ambitionen att förbättra patienters tillfredsställelse med aspekter kring information och delaktighet vid onkologiska kliniken på Karolinska Universitetssjukhuset. Personcentrerad rapport (PCR) äger rum vid byte mellan förmiddags- och eftermiddagspass. Sjuksköterskan som avslutar sitt pass, sjuksköterskan som börjar sitt pass, och patienten genomför överrapporteringen tillsammans. Rapporten har sin utgångspunkt i patientens önskemål, frågor och prioriteringar och syftar till att skapa en gemensam plan för det kommande dygnet.

Det övergripande syftet med avhandlingen var att identifiera och beskriva konsekvenser av att implementera och använda PCR i onkologisk slutenvård. De specifika syftena var att:

- Undersöka om PCR kan påverka patienters tillfredsställelse med vården, jämfört med traditionell rapport (beskriven ovan).
- Undersöka om PCR kan påverka patienters uppfattningar av information från sjukvårdspersonal.
- Beskriva övriga tänkbara konsekvenser av personcentrerad rapport som individualisering av vården, hälsorelaterad livskvalitet, samt aspekter av informationsutbyte och patientsäkerhet.
- Beskriva sjuksköterskors uppfattningar och erfarenheter av att arbeta med PCR i onkologisk slutenvård.

9.2 METODER

Personcentrerad rapport utvärderades på tre onkologiska slutenvårdsavdelningar. PCR infördes stegvis, först på en avdelning, och senare på de två andra. Avhandlingen innehåller fyra artiklar (**Artikel I-IV**) vilka utgår från tre olika studier på avdelningarna. **Artikel I** och **IV** utgår från en tvärsnittsstudie med två mättillfällen, där totalt 325 patienter besvarade frågeformulär om tillfredsställelse med vården, information, och hälsorelaterad livskvalitet. Jämförelser gjordes mellan patienterna som vårdats på avdelningen där PCR användes, och de som vårdats på avdelningarna där man inte använde PCR. Ytterligare en tvärsnittsstudie med syfte att undersöka konsekvenserna av PCR på längre sikt genomfördes två år efter den första datainsamlingen, **Artikel III**. Studien genomfördes på de två avdelningar som fungerat som jämförelsegrupp i den första studien, men där sedan PCR infördes. Nittio patienter besvarade frågeformulär om tillfredsställelse med vården och i vilken utsträckning de uppfattade att vården var individualiserad. Svaren jämfördes med data från **Artikel I**. Patienter som deltog i **Artikel I, III** och **IV** var över 18 år, hade en cancerdiagnos, hade vårdats på avdelningen i minst tre dygn, och förstod svenska. Patienter som vårdades i livets slutskede, och de som hade kognitiva problem tillfrågades inte att delta i studierna.

För att undersöka sjuksköterskors uppfattningar av att arbeta med PCR genomfördes en kvalitativ studie, **Artikel II**. Totalt intervjuades 11 av 13 sjuksköterskor, ungefär två år efter att PCR införts på de avdelningar där de arbetade. Intervjumaterialet analyserades och tematiserades genom innehållsanalys.

9.3 RESULTAT

Gällande patienttillfredsställelse visade resultaten i **Artikel I** inga statistiskt signifikanta skillnader i tillfredsställelse med vården mellan patienterna som haft möjlighet att delta i PCR och de som inte hade det, med ett undantag. Skalan ”Utbyte av information vårdpersonalen emellan” skattades högre av patienterna som vårdats på avdelningen där PCR införts. I uppföljningsstudien (**Artikel III**), angav patienterna som vårdades på avdelningar där PCR införts högre tillfredsställelse med både personalens informationsutbyte, och den informationen som de fick av sjuksköterskorna, än de som vårdades på avdelningar där traditionell rapport användes.

Inga skillnader observerades mellan grupperna avseende hälsorelaterad livskvalitet eller hur patienterna skattade mängden information de fått under sjukdomstiden (**Artikel IV**).

I intervjustudien med sjuksköterskor (**Artikel II**) framgick det att sjuksköterskorna föredrog PCR framför den gamla modellen där patienterna inte hade möjlighet att delta. De uttryckte

dock oro för patienternas integritet i samband med rapporten, och osäkerhet kring hur de skulle hantera patienters närstående. PCR ansågs som mer patientsäker, framför allt för att sjuksköterskorna tidigt under passet träffade patienterna och kunde kontrollera exempelvis infarter, såromläggningar och pågående läkemedelsinfusioner. Sjuksköterskorna bedömde att patienterna fick mer och bättre information i samband med PCR. De såg dock patienterna främst som mottagare av information, snarare än som deltagare i vården vilka också bidrar med information. Sjuksköterskorna angav att patienterna blev mer delaktiga i vården genom PCR, men beskrev också egna svårigheter och hinder för att involvera patienterna i tillräcklig utsträckning.

9.4 SLUTSATS

Sammanfattningsvis kan konstateras att PCR kan ha positiva konsekvenser för patienters tillfredsställelse med vården, mer precist avseende sjuksköterskors information och informationsutbytet mellan vårdpersonalen. PCR tycks inte påverka patienters hälsorelaterade livskvalitet eller deras uppfattningar av mängden information de fått under sjukdomstiden. Resultaten från studierna tyder på att implementeringen av PCR tar tid, och att utvärderingar bör göras även med ett längre perspektiv. Intervjuerna med sjuksköterskor visade att de föredrar PCR, men att det finns utmaningar med att involvera patienterna i rapporten.

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